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**The Moving Landscapes of Learning Disability**

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**UNIVERSITY**  
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**Thesis submitted for the degree of Doctor of Philosophy**

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As I sit down to ponder my acknowledgements I've come to the realisation that I never actually thought I would ever get to this point, and I find myself in the unusual position of not being sure what to say.

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## **Declaration**

I declare that this thesis is the result of my own work, except where explicit reference is made to the work of others. This thesis has not been submitted for any other degree at the University of Glasgow, or any other institution.

Victoria Louise Murray

22<sup>nd</sup> January 2018

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### **List of Abbreviations**

PWLD	People With Learning Disabilities
GG&C	Greater Glasgow and Clyde
TKTL	The Keys to Life
SAY?	The Same as You?
SCLD	The Scottish Commission for Learning Disability
SLDO	The Scottish Learning Disability Observatory
R&D	Research and Development
LDLT	Learning Disability Liaison Team

## **Abstract**

Most adults are able to take some control over where they live and are able to reflect on their migration histories, those places where they have lived and worked, and those places where they might aspire to live in the future. These life altering decisions have been negotiated either autonomously or in conjunction with significant others in their lives. For some adults, most notably those with learning disabilities, these life decisions are partially, if not wholly, made for them by others. It is therefore the aim of this thesis to uncover more about the decision-making opportunities afforded to people with learning disabilities regarding their home-spaces as they navigate 'moving landscapes' which they have perhaps not envisaged for themselves. Through the themes of decision-making, movement and belonging, this thesis works towards an up-close and in-depth study of residential spaces for people with learning disabilities as they traverse landscapes not always suited to their physical, mental and political needs.



Ronald McClelland (2015) *Home*

## Chapter 1

### Introduction

Most adults are able to take some control over where they live, to make decisions over where exactly they dwell and, as a consequence, to reflect on their migration histories. The mere mention of home can inspire vivid accounts of those places where they have lived and worked, or not (Hall, 2004), the reasons behind their moves or non-moves, and maybe even including those places where they might aspire to live, work and belong in the future. These life-altering decisions have been negotiated either autonomously or in conjunction with significant others in their lives. For some adults, however, most notably those with learning disabilities, these life decisions are partially, if not wholly, made on their behalf. It is therefore the aim of this thesis to uncover more about the decision-making opportunities afforded to people with learning disabilities regarding their home-spaces as they navigate 'moving landscapes' which they have perhaps not envisaged for themselves.

Historically, people with learning disabilities (PWLD) have had few opportunities to contribute to decision-making, especially regarding where they live. Their residential movements have been entangled within medically imbued political frameworks, which sought first to remove PWLD from the corpus of society, then to (re)place them within communities arguably not suited to their needs (discussed in more detail in Chapter 2 and Chapter 3). The closure of long-stay institutional spaces for PWLD was supposed to provide a better quality of life through increasing normalisation agendas (Hall and McGarrol, 2012), but, as Myers *et al* (1998) have noted, community presence and availability of opportunities do not directly correlate with genuine participation by PWLD within the communities in which they live; if, indeed, this should be a marker of the quality of life of

PWLD. It is, therefore, a key tenet of this thesis to discover more about the lived realities of PWLD as they encounter mobile residential experiences of and at home.

Massey (1993), in her critique of 'time-space compression' (Harvey, 1989) as the speeding-up of time-space connectivity under capitalism, noted that the ability to move and to undertake certain types of movement is "socially differentiated and unevenly distributed" (Dufty-Jones, 2012:210). Ong (1999:11) further adds that the notion of everyone being able to take "equal advantage of mobility" is entirely misleading. Combining notions of home and mobility, Blunt and Dowling (2006) argue that the static rootedness of home, suggested by Heidegger (1993), can be usefully unsettled when mobility is understood as a function of the "(re)production of meanings of home" (Dufty-Jones, 2012:212). As such, it is central to the core aims of this thesis to probe the mundane, yet in various ways profound, realities of life with a learning disability as those affected seek to navigate 'differently normal' lives (Hanson and Philo, 2007) around different residencies and homes.

Saunders and Williams (1988) suggest that home is the place in which the brick and mortar of the house fuses with the "social unit of the household", household here being used as opposed to family which, it is argued, describes only one type of household. From this perspective, the home becomes a socio-spatial system in which one part (the physical structure) cannot be represented without the other (social content). Porteous (1976:383) adopts a psycho-social stance which argues that home is primarily the individual experience of home, providing "identity, security and the stimulation of its occupants", an idea which is undoubtedly problematic for those with learning disabilities since many of the 'home' spaces which they occupy are not solely their own, can be unstable and are often constricting. Addressing this point, Giuliani (1991) identifies home as

an emotive space which therefore impacts on the quality of attachment to community and neighbourhood. Gurney (2000:34), meanwhile, describes home as a warehouse in which “grief, love, regret and guilt” are simultaneously felt, experienced, collected and understood, so creating a “powerful domestic geography, which, in turn sustains a complex and dynamic symbolism and meaning to rooms and spaces”. As such, Easthope (2004: 135) argues that home is both socio-spatial and psycho-spatial; and so, to understand a person’s connection to home is to begin to recognise their “social relations, their psychology and their emotions” through which lived experiences can be understood. If we are to accept Prohansky *et al*’s (1983:60) assertion that the home is the “place of greatest personal significance”, alongside Bachelard’s (1999:72) belief that “a key element in the development of people’s sense of themselves” is in belonging to a place, then an understanding of the moving landscapes of PWLD can open new pathways to knowledge about the daily lives of PWLD historically, now, and in the future as they experience movement, decision-making and belonging.

At this juncture, it is pertinent to introduce the reader to Lawrence<sup>1</sup> (pictured below in figure 1), a 70 year old gentleman with moderate learning disabilities. Traces of Lawrence’s life are narrated throughout this thesis as a life which perhaps most closely resembles the residential trajectory which might be expected of a person with learning disabilities of his age; namely, residence in institutionalised hospital environments and stays with various family carers. But Lawrence (70)<sup>2</sup> also represents a new generation of PWLD experiencing home spaces outside of the institution and ‘in the community’ in a UK context of austerity and public sector roll-backs,

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<sup>1</sup> Lawrence is the only name within the thesis that does not have a pseudonym, as per his signed permission.

<sup>2</sup> Numbers in brackets indicate the participant’s age and are used throughout the thesis on the first instance within a paragraph where their name is mentioned.

which arguably continue to reduce choice and opportunity for PWLD (Power *et al* 2016; Power, 2014; Hall and McGarrol, 2013). Working closely



**Figure 1.** Showing case-study participant Lawrence at home as depicted in his photo diary (with Lawrence's permission)

together to develop residential time-lines, photo diaries and residential case studies (the creation of which are discussed in Chapter 3), I not only learned a lot about Lawrence's personal experiences of movement, belonging and decision-making – the main empirical themes which bond the thesis – but about the potential for such research methods to give voice to PWLD. Lawrence's voice will continue to punctuate the thesis in the hope that the reader finds his experiences as illuminating, moving and thought-provoking as I did upon hearing them for the first time. Lawrence does not sensationalise his life, calmly reflecting on his experiences of traversing changing landscapes of care provision, offering gentle insights which prioritises the positives, even in the acknowledgement of the political structures and policies which have failed him in many ways; some of which he has neither the want nor the capacity to understand. What Lawrence adds to the narrative is a strong sense of the effects of changing structures of home and care across the life-course of PWLD and the myriad ways in which the small-scale

intricacies of home and belonging are tied to large-scale policy creation, development and implementation.

Framing these ideas, Chapter 2 begins with a consideration of the importance of place for PWLD, tracing routes out of the institution and into community settings. Moreover, this chapter begins to grapple with the terms 'inclusion' and 'exclusion', exploring their relationship to place and their role in the embodiment of PWLD. Developing this theme, place and identity are considered, drawing together how PWLD position themselves, and are positioned as, marginalised groups in mainstream spaces. Finally, Chapter 2 explores key links between home and place, beginning with the phenomenological underpinnings of home spaces which recognise the fluctuating dynamic between people and their place of dwelling. Taking a humanist turn, home and identity are unpacked, underlining home as a space in which power is enacted from the outside and within, and in which power is produced, circulated and acted upon. Growing from this, Chapter 3 turns to consider the practicalities and possibilities for researching *with*, not merely *on*, PWLD. It begins with a discussion which addresses attitudes to learning disability which have often rendered PWLD quiet in the research process, and in so doing, it is acknowledged, the chapter covers a breadth of issues to do with the history, theory and ethics of researching on learning disabilities which goes beyond what might normally be included in a 'methods' chapter. This chapter then works to outline the funnel-structured methodologies utilised within this project, used best to represent those learning disabled voices so important in understanding residential landscapes at both the wider political and intimately personal scales. Touching on the ethical processes involved in gaining access to PWLD, Chapter 3 stands to show that protectionist attitudes towards PWLD can preclude them from taking part in research for

which their input is invaluable, and which is therefore compromised without their input.

Moving beyond academic framings of learning disability in research, Chapter 4 begins with a discussion of the spatial practices of policy-making, aiming further to understand how the lives of PWLD in Scotland and the UK have been impacted by policies which aim to instruct on where PWLD should live. First, tackling the spatial practices which sought to house learning disabled bodies away from the general population, the chapter traces the learning disabled body in Scotland into the institution, before outlining those political discourses which finally led to the closure of specialised institutions and the introduction of community-based care. In particular *The Same as You?* (2000) and *The Keys to Life* (2013) are addressed as pivotal Scottish Policy frameworks which have carved out a social-based care landscape different in certain respects to the commodified care evident elsewhere in the UK (Hall, 2004). Finally, the chapter 'maps' those respondents taking part in the study, simultaneously aiming at getting to know the sample in greater detail and to picture the spatialising of care as it is now enacted in the community.

Concentrating the focus of the thesis yet further towards the personal life experiences of PWLD, Chapter 5 delves into the art of decision-making, discussing notions of support and control. The chapter emphasises positive and negative experiences of decision-making, identifying social and personal barriers which influence the small and large-scale mobilities of PWLD. Notably, attention is turned to decision-making and home, getting to the bottom of why residential decisions are made, or not made, and how these decisions are supported by parents and carers. Emotional attachment to home is also illustrated, underpinning connections between space, home, identity and decision-making, and further highlighting the need for

PWLD to be given ample opportunity to make informed decisions about issues, both small and large-scale, which affect their lives.

Moving on from decision-making, Chapter 6 examines movement, drawing on not only the large-scale residential landscapes of where PWLD have lived and do live, but also the small-scale movements at home which adds to what is known about the 'abnormally normal' (Hansen and Philo, 2007) everyday lives of PWLD. Why, where and when people move is incredibly telling with regards to how PWLD self-identify and how they experience friendship, community and belonging. Importantly, non-movement is also approached, uncovering those restrictive personal and political barriers which hinder and, potentially, stop movement at various scales for PWLD, conveying the disruptive, and often distressing, experiences of unpredictable movement. Arguments are further advanced by discussion of movement of, and also at, home, uncovering those residential landscapes which impact mobility and, conversely, stasis.

The final empirical chapter, Chapter 7, takes up the notion of belonging, attempting to unpick the complex ways in which community belonging can be comprised of a number of personal experiences and structural frameworks, highlighting the uneven landscapes of care and, moreover, opportunities for decision-making, belonging and movement faced by PWLD. Barriers to belonging are also outlined, providing a critique of the apparent straightforwardness of community involvement and inclusion. Again, home is brought to the fore, considering the multiple opportunities for, and barriers to, belonging in a number of home settings, be that family home, group home or alternative residential space. The thesis is brought to a close in Chapter 8, bringing together the three main themes of decision-making, movement and belonging in order to think critically about the residential mobilities of PWLD. The development of key themes

emerges here, bringing forth identifiable recommendations for policy and learning disabled-related theory.

As a note on terminology and recognition of the various, at times politically controversial, terms by which PWLD have been known in the past and currently, 'learning disabled' will be the term used throughout this work to reflect the participants who have taken part. Oliver (1996:43) has, quite rightly, pointed out the disabling effects of language, in particular how language can be used to "shape meanings" and "create realities" and, indeed, the work undertaken within this thesis has sought properly to reflect the individuality of disabled lives as described by those who would consider themselves to be learning disabled. Zola (1993) has argued for the term 'people with disabilities', not solely as a way of addressing political correctness, but rather as a way simply of putting people first. Like Corker (1998) and Shakespeare (1996), Zola (1998) has argued that there should be no formal, universal term which is exclusively entangled within the social or medical models of disability. Instead, there should be an understanding of 'learning disability' as a fluid and multifarious term which can apply to different people with learning disabilities, in different places and at different times. With this in mind, I have chosen to echo the thoughts of Ward and Flynn (1994) by selecting a term in which people with learning disabilities themselves have had some stake as part of the definitional process, recognising 'learning disabled' as the chosen language of charities and advocacy groups. Within this terminology I include those with mild, moderate and severe learning disabilities including Dyslexia, Downs Syndrome and Edwards Syndrome. Where historically appropriate, terms such as 'idiot' and 'lunatic' have been used.

## Chapter 2

### The importance of space, place and home:

#### Review of relevant literature

Through a reading of the literature surrounding the topic of learning disability, several themes stood out and as such this review of those literatures has been structured around these topics. First of all, the concept of place is considered, and the reason why it plays an important role for the geographer thinking about the spaces of people with learning disabilities. Thinking about places for PWLD, the chapter discusses the initial out-placement of the learning disabled body from the proliferation of the 'idiot asylum' from the mid-1800's, aiming to understand why specific places for PWLD were carved out and the ways in which these were supported culturally and politically. Documenting the road out of the asylum (or residential institution) in the late-1960's, deinstitutionalisation is then discussed, charting the move to the 'care in the community' model most easily aligned with today's care landscape. Moving on the chapter takes a conceptual turn, building on understandings of place and identity and the important connections between the two for those with learning disabilities, using a phenomenological lens to begin to understand learning disabled interactions with spaces of 'home'. Finally, it turns attention to the little addressed concept of 'home' within the learning disabilities literature, and the ways in which the concept of place might assist in opening up questions of home for the geographer studying learning disabilities.

#### ***Why is place important in learning disability geographies?***

Place is considered a geographically important concept, since it denotes many of the spaces and places<sup>3</sup> in which humans live,

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<sup>3</sup> Within academic (capital-G) Geography, it is important to note the importance of, and distinct difference between, 'place' and 'space'. While 'place' can refer to

construct and maintain their lives at different scales and at different times. Considering place within the study of learning disability has the potential to open up knowledge of different worlds which operate within, through and despite some of the socially constructed barriers placed in the way, enlightening a better and fuller understanding of how a 'place for PWLD' is carved out within a society essentially organised for those considered able-bodied and able-minded. Macintyre *et al* (2002:125) study "place effects", adding weight to Andrews *et al's* (2012:1) assertion that place matters to health, suggesting that "where one lives, works, socializes and how one uses the environment has profound health implications". It is therefore essential when thinking about the intricacies of the everyday experiences of people with learning disabilities (PWLD) also to consider their relationship with the places and spaces that they encounter.

#### *Moving into the institution*

Historically, PWLD have been spatially displaced by mainstream society, through a time of institutional isolation literally on the margins of society in the mid-1800's, to a wall-less, socially produced and maintained set of practices which arguably continue to limit the social, cultural and political experiences which are available for PWLD to date. The initial 'out-placement' of the "intellectually disabled body", as Philo and Metzel (2004) term it, moved this population out of the city and so also 'out of the mind of the city'. This displacement was apparently sought for the greater good of society, since the

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specific demarcated and bounded regions or areas, within geographical thinking, place has the potential to be more conceptual. *The Dictionary of Human Geography* (2009) suggests that: "to be a place necessarily has meaning"; "place as becoming locale" through continual temporal shifts and changes; "the de-centred global sense of place" which understands globalisation as a factor which affects the ways in which place is experienced and understood. 'Space', on the other hand, involves the understanding of the "intricate connection between power, knowledge and geography" which has the potential to change the ways in which space can be conceptualised.

unpredictability of their behaviour was symbolic of the 'irrationality of their state of mind' which was at odds with the rational, controllable, 'sane' population (Philo and Metzel, 2004). These dichotomies between 'us' and 'them' continued after deinstitutionalisation and, so Hall and Kearns (2001) argue, the consideration of spaces for those with learning disabilities have been arranged in two temporal folds: inside 'the asylum'<sup>4</sup> and outside the asylum<sup>5</sup>. They further argue that the asylum asserted "symbolic influence", acting as a "container" for those deemed mentally deficient and as such marking these individuals as 'unfit' for inclusion within a wider civilised and rational society. The resulting stigma made the act of deinstitutionalisation a space of public contention, shifting the concern of the geographer towards post-asylum, community spaces for PWLD.

#### *Moving out of the institution*

While deinstitutionalisation aimed to re-establish previously isolated groups within the community, there are several ways in which PWLD continue to be excluded from fully participating within mainstream spaces as ideas about where people with learning disabilities *should* live shifted. Wolch (1980:330) argues that deinstitutionalisation has reinforced a "co-locational relationship of service dependency", highlighted by Power (2008:835) as the underlying "clash between care and dependency". Wolch (1980) argues that this clash has caused an "enforced [social] poverty" since, as Nerney (1998) suggests, PWLD experience "isolation from the community, lack of real friendships and relationships, and lack of disposable income", a very real concern of many of the parents of those with learning disabilities (see Latib *et al*, 1984; and Larson *et al*, 1991). Metzel (2005:94) suggests that deinstitutionalisation merely redistributed PWLD, creating a new

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<sup>4</sup> Elsewhere in the thesis 'the asylum' will be discussed in terms of the 'institution'.

<sup>5</sup> Indeed there is a much longer pre-history when PWLD, maybe identified as 'idiots', 'fools' or 'brutes', were not institutionalised, perhaps left to wander and fend for themselves as best they could.

“asylum without walls” within a community setting, with many PWLD living within easy reach of service support and old social ties without integrating into a wider (non-learning disabled) community setting. This point is furthered by Hall and Kearns (2001:240), who argue that PWLD remain invisible within the overall population since deinstitutionalisation failed to empower them, and instead inadvertently constructed a new system of control which assumed both that all PWLD were unable to lead independent lives and that financial and logistical constraints on policy could not really accommodate the views and preferences of PWLD.

Further spatial differentiation is suggested through Metzel’s (2005) US-focussed discussion of the growth of ‘special’ schools and workshops for those with learning disability, provided through voluntary organisations. This development effectively re-grouped PWLD within a different institutional settings and provided a space equally as “insular and isolating” as ‘the asylum’ (2005:96). Hall and Kearns (2001:240) further add that the isolation caused by deinstitutionalisation is exacerbated by working and living within wider communities which show an unwillingness to “understand non-standard forms of communication”, and which thereby maintain a strong sense of difference. As such, PWLD are unable to become a visible part of the ‘street space’.

#### *Deinstitutionalisation and a move to ‘care in the community’*

Concentrating on the Irish context of care in the community, Kenny and Power (2011:422) study the ground-level implications of what they term “hands off” provision of health service delivery in the early 2000’s. They argue that states are increasingly unable to manage the provision of adequate health and social care, and so non-profit organisations provide a key point at which this gap is bridged. The issues with these services are inherently spatial since it appears to be

their geographical spread and boundaries which cause most problems for PWLD and their families who use the services (Power, 2008a; 2008b; 2009). Decentralisation of services away from state control was an attempt, as Hood (1991:8 in Kenny and Power, 2011) suggests, to rid the system of a claim to universality, “allowing the system to properly reflect those who it supports”, so overcoming “the limitations of centrally controlled national planning by delegating greater authority to officials working in the field, closer to the problems” (De Vries, 2007:197 in Kenny and Power, 2011:422). Moreover, decentralisation would afford these organisations “flexibility, responsiveness and the ability to represent diverse improvements” in how these services are delivered (Kenny and Power, 2011:423). This vision is not, however, the reality of the care experience ‘on the ground’ in Ireland.

Additionally, many critics of a top-down approach to community care argue that grass-roots, spatially and geographically organic approaches are “more people-friendly than those emerging from bureaucracies” (Kenny and Power, 2011:424), since they are better placed to serve sub-groups within their local contexts. As such, these groups should be more open to change and development, and therefore better able to serve the end user. Kenny and Power (2011:424) argue, though, that the welfare state is often reluctant to hand over control to local agencies and therefore the end user is often “overlooked and negatively impacted”. In saying this, they also critique the “relaxed system” of geographically dispersed and locally produced organisations within the Irish context which has allowed the state to distance itself from the “problem of the handicapped” (Kenny and Power, 2011:424), leaving many PWLD, their families and carers in vulnerable positions. This relaxed, decentralised, barely accountable and highly autonomous system has created information deficits which makes it difficult for carers to plan futures with their

PWLD, since “opaque, non-responsive” organisations fail either to include PWLD within the decision-making process, or to engage with information networks relevant to PWLD, leaving services generally underdeveloped (Kenny and Power, 2011:425).

Likewise, Kenny and Power (2011) find that the control of landscapes of care provision by particular organisations has caused problems of access for particular services which centre on place. Firstly, being accepted within some facilities was an issue, with many PWLD unable to find suitable training or day care places within their ‘catchment area’. Secondly, when allocated places on their behalf by organisations, facilities were often unable to cater to any additional behavioural or medical issues which might arise in conjunction with learning disabilities, so leaving out those who did not ‘fit’ within their particular services and crucially ignoring the presence of so-called ‘co-morbidities’. Carers were left with a ‘take it or leave it scenario’ where individuals with multiple additional needs could not and would not be accepted into support networks (Kenny and Power, 2011). Yet more problems of place also arose when carers attempted to ‘cross the county boundary’ in search of more appropriate care environments. Since funding is gained by autonomous organisations and not by individuals themselves, funding is unable to travel with the PWLD in order that they should receive the best care available for their needs, leaving them, as Kenny and Power (2011:427) put it, “geographically trapped” and so further isolated. It is hence obvious to see the various ways in which place as a geographical location matters when it comes to service provision for those with learning disabilities.

From a mainland British perspective, Hall (2007) recognises that place-based health policies, such as healthy living centres and health action zones, have acknowledged the connection between physical environment, housing, employment, participation and health, but that there are several ways in which these initiatives fail those with

learning disability. Firstly, it is argued that health is still largely conceptualised as a biomedical status which can be tied to subjective measures of mortality and morbidity (Hall 2007). This framing ignores other possible outcomes which are less easily measured but which might be more achievable for PWLD, such as empowerment and wellbeing. Secondly, Hall (2007) argues that such policies reflect narrow targets based on national scales which generally do not represent PWLD. Additionally, place-based initiatives often target the majority of the population but, since they are not overwhelmingly to be found in particular neighbourhoods – not withstanding some evident unevenness in their spatial-residential distribution (as also shown in the Glasgow case in Chapter 4) – they often remain unaccounted for. Moreover, PWLD are already “socio-spatially” excluded and therefore specific place-based schemes tend to represent existing power networks, further leading to solutions which suit the widest cross section of society. Critically, the flash-in-the-pan funding which these health action areas receive fails to represent PWLD since their condition is unlikely to improve across the short period of time in which health related assistance and funding is available (Hall, 2007:132).

Geographical variances in the learning disabled experience of space are further affected by rural to urban discrepancies, which Andrews *et al* (2012) suggest occur in how support and services become available for PWLD. They argue that the rural experience of learning disability can be physically isolating as well as socially, since most relevant services seem to be concentrated within city environments. This point is furthered by Hall (2005), who suggests that rural experiences of learning disability can cause further isolation without networks of established connections to others who have learning disabilities. Moreover, he highlights the difficulty that this rural-urban divide poses to constructing personal and collective identities, which

allows many PWLD to represent themselves (or other PWLD) in a way which “embraces positive self perceptions” (Hall, 2005:112). Essentially, it is easier within urban areas for PWLD to ‘build’ their own communities and, in a sense, achieve a measure of ‘voice’.

### *Constructions of place in learning disability geographies*

It is worthwhile recognising that place is not simply a static location which waits to be brought to life through use, but rather is ever-changing and differently experienced by the individuals who weave and flow their paths through and around these places. Discussing the very specific concept of walkability, Andrews *et al* (2012:4) critique the focus on walking as purely exercise, since it does not account for the diverse bodily and emotional spatial experiences which can occur when a particular body moves through a variety of places and spaces. It is particularly important, when considering the social, cultural, political and geographical segregation of PWLD, to understand the “intensely embodied and emotional experience” of navigating through and between ‘exclusionary spaces’ which PWLD tend to occupy. Furthermore, it is argued that place and its perception by individuals are inextricably bound with the structures, practices and cultures of movement. As such, Andrews *et al* (2012:6) maintain that health geographers, in particular, must attend to the ideas of movement in place which speaks to the “materiality of the body” without splitting it from its connection to the mind, and so working towards an interrogation of “embodied subject positions in contemporary society”.

Place can also be conceptually considered, bringing forth social, cultural and political frameworks which reproduce knowledge about learning disabilities and essentially establish who is considered ‘in-place’, constructed as ‘Same’, and who ‘out-of-place’, constructed as ‘Other’ (Cresswell, 1996). Hall (2004:298) argues that a continued

marginalisation of PWLD results in, and continues to reflect on, “opportunities for employment, less choice over housing, fewer options in education”, as well as the common experience of “discrimination abjection, abuse, poorer health and a lack of control over key decisions”. He further argues that little is understood about the “private spheres” in which PWLD live their everyday lives, a product of a “deeply embedded sense of mental difference” (Hall, 2004:298). This ‘blind spot’ in “social presence” (Hall, 2004:299) is arguably complicit in creating that socially produced ‘asylum without walls’ mentioned earlier, which continues to exclude and limit the social, cultural and political experiences available to those with learning disabilities (Philo and Metzger, 2005). Madanipour *et al* (1998:22) suggest that these exclusionary practices are in fact more multi-dimensional than might be initially understood. Various entanglements of exclusion in terms of political representation and access to employment and resources, combined with forced integration into “common”, “acceptable” cultural processes, all serve to generate specific socio-spatial representations of learning disability which are not necessarily helpful (Hall, 2004; 2005). The notions of Inclusion and exclusion are in themselves conceptual constructions of place, since, as Sibley (1998:119) suggests, these concepts require that PWLD exist outwith mainstream society. Furthermore, it is suggested that the term ‘inclusion’ requires that PWLD “conform to a mainstream notion of ‘normality’, through bodily behaviour and appearance, social location ... and/or economic engagement”. Practices of exclusion from these spaces maintain a social order in which the threat of an ‘unpredictable’ disabled person is kept to a minimum, leading to increasingly small worlds which PWLD are comfortable in inhabiting. Through an understanding of the “complex everyday geographies” of PWLD, Hall (2004:300) suggests that alternative “imaginings” of inclusion can begin to be understood and, more importantly, so too the role which place and space play in these

new constructions of 'in-place'. Samers (1998) argues that, in order to be excluded, a group must be seen as necessarily undesirable, but the narratives of inclusion and exclusion explored in many of Hall's papers (2001; 2004; 2005; 2007) show that PWLD often choose to socialise within spaces where they feel safe – often with other PWLD – not in which they feel included. By removing themselves physically from potential or perceived spaces of intimidation (such as specific pubs and cafes), PWLD have shown that they are able to construct their own spaces through a personal agency of self-exclusion which creates “their mental map of exclusionary and inclusionary spaces” (Hall, 2005:108).

Although conceptual, these theories reflect upon the real, physical geographical places which PWLD inhabit. Hall (2005) builds a picture of learning disabled constructions of 'safe space' which suggests that these 'hubs of safety' become separate islands of activity, with many PWLD avoiding walking between these spaces or using public transport. Getting from point 'A' to point 'B' is not necessarily a leisurely or enjoyable mobility from one place to the other, but rather it becomes a 'put-up-with' necessity in order to enjoy and experience site 'A' or 'B'. This occurrence leaves behind distinct 'pods' of safety and comfort, rather than a network of flows between and within spaces and places. The lines of possibility (both positive and negative) between these spaces of safety are left un-experienced, and as such potentially new/different socio-cultural interactions of a positive nature are also avoided. Power and Bartlett (2017:15) develop this idea further by suggesting that PWLD can be active agents in the “cultivation of safe havens” within and outwith their immediate communities. This frames PWLD not as steering away from inherently exclusionary spaces, but rather being actively involved in the finding and managing of their own “healthy and inclusive” environments (Power and Bartlett, 2017:16). This point expands on O'Brien and

Lyle's (1987) distinction between community presence and participation, usefully opening up how we are able to think about the power of PWLD to create community.

Power (2008a:840) also highlights routine as another way in which space is structured and maintained, using Wiles (2003) to suggest that it ensures "the comfort of the recipients through structure" as well as "managing the demands of their day" and helping to "mitigate the stress of crisis". Parr (2000:225) further suggests that this organisation of space and time asserts the value of "intimate social and spatial worlds" which routinise and compartmentalise "out-of-bound" places with "comfort zones", as a result "increasing marginalisation into even smaller spaces, on the outer fringes of the daily round".

#### *Place and identity in learning disability geographies*

Place can also be a determining factor of personal identity, with emotional attachment and experience arguably creating an embodied experience of self. Hall (2000) suggests that for too long the body has been left outside of the consideration of health geographers, with Longhurst (2005) suggesting that the body has become an insignificant 'Other' to the all-powerful mind. Through such thinking, then, it is no wonder that the label 'disabled' is most readily applied to learning disability, therefore leaving PWLD 'dis-abled' in reaching an identity beyond that which is socially and medically ascribed. In his article 'Blood, brain and bones', Hall (2000) shows that, throughout human history, society has struggled between the concepts of body and mind, fighting to understand that space which is medicalised, hidden underneath and out of view. Through the process of "intense medicalisation", Hall (2007:130) argues that the body of PWLD is often considered to be 'universally disabled' and therefore all ailments are considered an extension of the learning disability. This claim is furthered by Cooper (2004), who explains the low value and

expectations which are placed on PWLD. This assumption of low bodily worth through institutional discrimination trickles down from health professionals, to parents, carers and often the PWLD themselves, and as such it is easy to see why politicised learning disabled identity is not as strong as that associated with other forms of disability (Cooper, 2004). Speaking of the disabled body and mind in particular, Hall (2000) suggests that the learning disabled person, more than any other site, ignites the debate between biological and social determining factors, further fuelled by the development of the 'social model' of disability. This model, however, fails to account for "the body that we experience" (Hall, 2000:24), and instead Hall suggests an alternative theory which sees the body as social and the social as bodily through an understanding of the in-between spaces of the Cartesian mind-body split. While there is reluctance to admit the biological features of the mind and body due to an understandable concern about a resurgence of biological determinism, Hall (2000) believes that the body and mind can be brought back into studies of health and impairment. Furthermore, it is important to give voice, sight and texture to the everyday experience of people with a multitude of different learning disabilities by opening up the everyday learning disabled normality with which PWLD know and can identify: Hall (2000:26) argues that the "social context becomes an integral part of the experience of the biological process". This recognition would therefore open up new spaces for identity in which complexities, intricacies and often struggles of everyday lifeworlds become part of the whole picture of the person, who can then become 'also learning disabled' as opposed to 'learning disabled and also...' and, in this way, give weight to label 'learning disabled'. Through a focus on the representation and identity of the body and mind as sites for re-inscribing social processes, Hall (2000:28) believes that health geography lost the ability to understand the "fleshy reality" which is "central to our experience of health and impairment".

Through a reclaiming of these 'fleshy spaces', Hall (2000) suggests that the body is in fact a "complex interaction between society and biology" which gives scope for geographers and others to understand the body and mind as an essential component of social experience and, therefore, the complex constructions of personal identity.

The ability to gain a clearly distinguished individual identity is sometimes difficult for PWLD since their daily geographies are bound up in a limited spatiality of co-existence with carers and parents. As such, Power (2008a) suggests that PWLD and their significant others/professional carers run the risk of two lives inextricably bound to the other, creating almost hybrid identities which makes independent identity all the more difficult. Promoting an autonomous identity has also been made difficult through site-specific encounters in the local community, with the inability of the 'awkward able-bodied person' to recognise that PWLD are not children (Power 2008a). Furthermore, the label 'disabled' closes the door to opportunities (not least employment) since it speaks so much to what a PWLD *cannot* do as opposed to what they *can* do. As has been previously discussed, lack of information and relevant education and information, aimed at and produced with and by PWLD, acts as a double edged sword, producing self-identities where PWLD are not aware of their potential for input and change. Additionally, Laws and Radford (1998) suggest that exclusionary practices through 'special' schools, group housing and 'suitable types of employment', although initially meant as *inclusionary* spaces, continue to marginalise PWLD and this in turn helps to reproduce the self-identity of PWLD. This situation creates a messy and knotted identity positionality, whereby the PWLD comes to know themselves by the ways in which they are seen by wider society, juxtaposed to the embodied reality of their abilities, likes, dislikes and experiences. Moreover, Hall and Kearns (2001:243) argue that this affects the level to which PWLD are empowered to make

change or contribute to policy development, and so they call upon researchers properly to incorporate and empower PWLD through the research process.

### *Identity and advocacy*

Some PWLD have exercised their right to an identity by establishing personal identities through social and political places and spaces. Self-advocacy is one way in which PWLD have begun to re-establish flows of community-based learning disabled understanding, giving PWLD the opportunity for agency within socially accepted and, crucially, spaces in which they may be listened to. Through collective action with groups such as People First and Enable (Hall, 2005), PWLD are able to give themselves a political positionality and identity, as well as to establish the 'voice' of learning disability (Hall *et al*, 2016). This self-advocacy seeks to raise awareness of a marginalised group, grossly under-represented in any decision making policies which affect their day to day experiences, although Hall (2005) does admit that this type of identity stand is probably limited in its potential to change the ways in which learning disability is thought about.

Identity as a PWLD can be further established through the creation of spaces of 'safety' where identification as having a learning disability can be "valued and strengthened" (Hall, 2004:303) through social connections and their 'collective narratives' (Parr, 1998; 2008). It is suggested by Hall (2004) that, for some, optional exclusion from 'normal' modes of existence allows the creation of comfortable places in which PWLD can control and maintain their environments, and seek to command a collective identity through the "development of networks of people, groups and spaces where leaning disability is accepted, valued and normalised". Moreover, Hall (2004; 2005) calls for a sustained critique of "employment-focussed social inclusion strategy" for PWLD, which insists upon placing PWLD within

environments of supposedly wider community inclusion. It has been shown, however, that inclusion is not necessarily synonymous with acceptance, and therefore simply situating people within the 'normal' socio-economic jigsaw does not mean that they will suddenly and without question feel or be seen to have an identity other than as a learning disabled person. Laws and Radford (1998) suggest that, since deinstitutionalisation, the "objective circumstances" of many PWLD have changed for the better, but the reality is that even within employment some PWLD experience exclusionary practices, while others opt to take on "non-paid, social or cultural work" (Hall 2005:108) which allows them to develop a working identity comfortable and acceptable to them as individuals. Power (2008a:814) believes that through finding safe spaces, such as day care centres, PWLD could be provided with a space in which they can learn to "assert their own needs and identities rather than cope with everyday exclusionary experiences", and to find spaces and places which "develop and nurture, at the very least, bodily and mental stability, at the very best, happiness and peace" (Hall, 2007:132; Power and Bartlett, 2017).

#### *A place called home in learning disability geographies*

Taking a phenomenological approach, Manzo (2003) begins to explore the relationships between people and place, arguing that place is entwined within the very act of existing. Tuan (1977) furthers this claim in his suggestion, echoing those made earlier in this chapter, that homogenous *space* only becomes *place* through meaningful interactions with humans which render it valuable. Similarly, Heidegger (1971) argues that dwelling is not an activity which is performed, but rather, is a way of existing. Pointedly, Heidegger (1971:146) asks, "Do the houses themselves hold any guarantee that dwelling occurs in them?"; and this is a particularly useful question for the research at hand.

A phenomenological approach to research is one which seeks, in its purest form, to describe rather than to explain, beginning the research process free from initial perceptions (Husserl, 1970) and attending, as Polkinghorn (1989:41) states, to the “configurations of experience”. As evidenced later within this chapter, this starting-point has been challenged by humanist and feminist thinkers who instead propose research in which the researcher is an active part of the interpretative process, not simply a passive data collector (Plummer, 1983; Stanley and Wise, 1993). As an approach to research, phenomenological framings bring respondents’ experiences to the fore, challenging normative perceptions and creating research with cultural and political weight, recognising Imrie’s (1996:145) claim that people with (learning) disabilities are not themselves “merely passive recipients of the built environment, but actively seek to challenge and change it”. So, how do those with learning disabilities exist in the world and how can their locational histories and experiences tell us more about the reality of their lived experience?

Recognising that relationships between people and place are dynamic and ever-changing, Manzo (2003:51) uses Seamon (1993) to discuss the correlation between “movement, rest and encounter”, arguing that the intersections between the three terms represent the dialectical processes which forms place as the foundation of our being. Buttmer (1980) speaks of these dynamics in terms of ‘home’ and ‘reach’, suggesting that emotional attachment to place is premised upon the interaction between home and the places outside of it. Case (1996) deepens this argument, suggesting that the contrast between the daily domestic routines and those experiences outwith helps to redefine individual thoughts regarding home. Phenomenologists such as Relph (1976) and Seamon (1981) have spoken of insideness/outsideness whereby ‘insideness’ occurs without self-conscious reflection and ‘outsideness’ occurs as a result

of a felt separation of self and place. Rather than simply reflecting proximity to home, this dialectic recognises the ever-changing nature of relationships with home by suggesting that relationships to place are never static nor final, but rather always in flux and constantly redefined. As such, it is essential that this research reaches out of the home and into those other familiar and important places which impact on how PWLD experience their domestic mobilities, sense of belonging and opportunities for decision-making.

### *Masculinist understandings of home*

Blunt and Dowling (2006:2) construct home as a “spatial imaginary”, a domestic crucible in which a set of interrelated and changeable ideas and feelings are contextualised and re-imagined across and between spaces and scales. Recognising the subjective nature of feeling ‘at home’ gives space for the feminist critique that the domestic environment can as easily be “oppressive and alienating” as it is “supportive and comfortable” (Blunt and Dowling, 2006:10); and it is therefore crucial in doing ‘geography of home’ that we, as geographers, explore home within and beyond the house, as well as avoiding any simplistic assumptions about home-space as necessarily always hospitable or even good for PWLD. Taking a humanistic standpoint, Dovey (1985) looks upon the house as a static entity, separate from, but constantly evaded by, wider social, cultural and political structures. This separation of a dwelling and its wider contexts, Blunt and Dowling (2006) argue, divorces home from the social processes in which it is involved, rendering individual experiences mute. As such, it is crucial that this research moves forward in the manner of Manzo (2003), in order to recognise the dynamic and changeable nature of people’s relationship to place, in particular the learning disabled individuals’ relation to their home-space.

Rose (1993) asserts that the humanistic understanding of home as an essential grounding of human identity is problematically masculinist, since it relies on the experiences of men and not women. In this way too, Bowlby *et al* (1997) argue that gender is critical to an understanding of home. Mackenzie and Rose (1983) argue that the process of industrialisation was dependent on the separation of the work and domestic spheres, and so feminist writers have sought to articulate the links which re-tie the two together. Blunt and Dowling (2006) point to feminist research in “empirically and theoretically” showing that home-spaces and imaginaries are not “exclusively private, familial or feminine”, so opening doors which shed light on the domestic spheres of others considered to be on the margins, such as those with a learning disability, and indeed casting aside normalised assumptions about life ‘at home’.

Discussing the home-space for women of colour, hooks (1991:148) asserts that home is, at times, nowhere, a space which is sometimes characterised by “estrangement and alienation”, and at other times “promotes varied and ever-changing perspectives” where one “discovers new ways of seeing reality, frontiers of difference”. This intriguing claim supports the notion that home is a fluid and mobile place, a contested site continually reshaped by “different axes of power” at a range of personal, community and political scales, so recognising that that the “intimate and personal spaces of home” are inextricably linked to wider power relations (Blunt 2005:4). As a site which is both physical and imagined, Rubenstein (2001) suggests that home is not merely locational but also emotional, with Easthope (2004:136) reminding us that, “while homes may be located, it is not the location that is “home””. Rather, home is a process of “creating and understanding forms of dwelling and belonging”, a space which is made manifest through the material interactions of everyday practices (Blunt and Dowling 2006:23). Miller (1998) states that social

worlds are composed through materiality and, as such, Blunt and Dowling (2006:24) suggest that a critical geography of home must also examine the material alongside the socio-political structures of dwelling (like class, deprivation and so on), advancing the claim that the objects in our homes, including the ways in which we use them, all serve to create home and its social differentiations. The latter point is easily illustrated in some of the empirical materials presented later.

Through home, then, we can begin to see how identity can be constructed through “lived and imaginative experiences” which in turn are produced by power relations both within and outwith the home (Blunt and Dowling 2006:24). Massey (1982), terms this state of affairs the “power geometry”, arguing that place is formed by a variable set of power-laden social relations which are played out in a certain location and impacted on by wider social and political discourses. It is important, as such, to continue to challenge normative notions about what is being and belonging ‘at home’, in particular unsettling what is considered normal at home for PWLD. Blunt and Dowling (2006) propose that home is multi-scalar and porous, representing just one location at which social relations and emotion intersect, and where such multiple identities can be made and contested. Marston (2000) expands on this proposal, suggesting that scale – like home, city, and nation for example – cannot be understood as singular but as relational to each other, so recognising the role of social, physical, cultural and emotional experiences.

#### *Identity and home economies*

Turning to the notion of home economies, Blunt and Dowling (2006:92) discuss the links between tenure, social division and identity, arguing that, like all processes of inclusion and exclusion, “the links between housing tenure and social disadvantage are complex and remain important”. Furthermore, they argue that home-

ownership is most closely aligned with dominant cultural notions of home, with home becoming a marker of independence which suggests that one is presumed capable of making and creating a safe, secure and welcoming home-space. Given that having one's home is culturally seen as the pinnacle of becoming a self-sustaining adult, it is not difficult to imagine that those with learning disabilities may also seek to own their own home. The problematic here comes in the use of the term 'capable', a contentious word which speaks to the ability to procure and maintain a home, something which many PWLD are unable to do for a variety of reasons, both structural and personal. Moreover, Bunt and Dowling (2006) also state that the more socially disadvantaged, such as PWLD, are more likely to live in deprived areas, therefore changing how one views and relates to home, work, friends, family, and future aspirations.

Blunt and Dowling (2006) suggest that the ideal Western notion of home is one which is essentially middle class and white and, as such, many of the normative ideas of home-as-haven are not experienced by those who fall outwith these categories. Moreover, they suggest that prevalent normative discourses have, in many cases, been underpinned by state policies and economic processes which limit the ability of those on the margins to gain access to suitable housing. While this idea is discussed in relation to African-American families in the US, many of the same barriers are undoubtedly experienced by those with learning disabilities through reduced access to the job market and to housing which suits their financial, physical and social needs. Gurney (1999) argues that suburban homes are assumed to embody the middle-class cultural ideal of home ownership which, in turn, signifies the material achievement of those who reside within. In home-making, then, many PWLD may also strive for this ideal in order to be more widely recognised as 'normal'. Blunt and Dowling (2006) expand on this possibility through discussion of "unhomely" spaces,

recognising the subjectivity involved in experiencing unhomely spaces, in homely ways. As such, it is possible that PWLD can feel at home within spaces more normatively defined as unhomely, such as long stay institutional facilities. It is important that this research focuses on the individual learning disabled experience of home, recognising that home can be both empowering and confining. This caution involves leaving behind assumptions about the intrusiveness of carers or restrictiveness of the family home, and instead must learn honestly about those residential moves and non-moves which matter most to PWLD.

Speaking of those with physical disabilities, Imrie (2004:760) touches on the tensions between ideal conceptions of home and the lived reality, most notably the conditional nature of the suitability or otherwise of the home-space. This ever-changing relationship between the home-space and its suitability is also relevant to research on home with PWLD, and calls for a critical understanding of the spaces inside the home, but also the potential for connections to other homes and with other people, places and communities of importance. Oldman and Beresford (2000:493) quote a family who have moved in to a purpose-built home for their daughter's needs;

If you've got your home right you can cope. This house is like a cocoon. It doesn't matter what's coming at us now. How can you make a tough decision in a house that is not a home?

The quote above neatly explains the importance of appropriate housing situations for those with disabilities (learning disabilities in my case), but notably also highlights the mobilities and options available when funding is accessible. Within the correctly supported home-space, those with learning disabilities can perhaps begin to build and confidently navigate around their homes and beyond, creating further

opportunities for mobility, decision-making and belonging. Furthermore, this quote touches on links between the home and the ability to make tough, or even sometimes trivial, decisions, an important consideration of this thesis, especially in Chapter 5.

Importantly, Manzo (2003) suggests that dwelling can be enacted across a number of places at a number of scales, recognising that the physicality of the house itself represents but one facet of the person. Highlighting the contrast between house and home opens conversation on the physical, social and political spaces which also come to bear on experiences and feelings associated with the home-space. Like Riley (1992:25), this research must come to understand that home as an “extraordinarily malleable concept” which may often displace the long held romantic notion of home-as-haven. Furthermore, Manzo (2003) encourages a more open approach to understanding home beyond the residence, which encapsulates more geographically sporadic locations which also inflect on feelings about home, including local neighbourhoods, ‘home’ settlements, regions and nation-states.

In opposition to the home-as-haven trope, Ehrenreich and English (1978:10) suggest that the proliferation of the public-private binary in relation to home has led to an exaggerated “emotional nobility” which fails to recognise that home residence can also encompass feelings of fear, tragedy, and pain. Marcus (1995) has referred to ‘home as trap’ to capture this alternative, unpleasant relationship between people and their home-space. Negative associations may also arise in the very mundane activities of everyday home life, with both LeFebvre (1974) and Relph (1974) discussing the oppressive and imprisoning possibilities bound up in place. As such, Relph (1976:6) has argued that any examination of the direct experience of place “must be concerned with the entire range of experiences through which we all know and make places”; a crucial concern of this thesis.

Considering home-spaces for PWLD, Hall (2005:110) finds that living 'independently' can be more oppressive than not, with constant intervention from third party carers as well as their intermittent, or sometimes constant, presence in what should be a private home space. For some, this intrusion has stunted the growth of their personal identity and autonomy which living independently was supposed to bring. It is even argued that closure of long-stay hospitals has left a gulf in the learning disabled community where networks of care and understanding once stood. This concern is furthered by Metzel's (2005) study into deinstitutionalisation in Baltimore, where many respondents with learning disabilities preferred to be re-homed within existing networks of carers and support workers already established in the vicinity of their ex-residential institution, something possibly occurring in one Glasgow sample explored in Chapter 4. This fact perhaps also highlights a failure to recognise the potential wants and aspirations of PWLD beyond the care needs of their disability.

Not all PWLD live independently, however, and Power (2008a:839) argues that, since the "space and focus" of daily activities are centred on the needs of PWLD, narrowed spatial lives can become focussed on the home-space, producing changeable representations of what 'home' means. Many carers interviewed by Power (2008a; 2008b) felt that a lack of support and ability to 'get away' creates a sense of isolation, enhanced by limited access to community care services as well as to "supportive networks of family and friends". Furthermore, the home here is viewed as a place away from engaging with the public life and as such comprises a respite away from spaces of discomfort and stigmatisation. Moreover, the home becomes a "site of caring" (Power, 2008a:840), institutionalising the private sphere and essentially changing the social meaning ascribed to home. "[S]pace and scale" are therefore seen as critical to Power (2008a:840) in establishing the "rhythms, routines and reorganisation" of the

home space, since the physical needs and behaviours of PWLD produce the specific configuration of home. Power (2008a) suggests that young adults with learning disabilities can find the home space to be characterised by “isolation, loneliness and imbued with different meanings”.

### ***Concluding thoughts***

It has been reiterated throughout this chapter that there is an intricate relationship between place and health, arising physically, socially and politically. Social and political separation between ‘us’ as non-learning disabled individuals and ‘them’ as PWLD has indeed impacted on where PWLD can and do live, both historically and contemporarily. As has been highlighted, a relatively ill thought-through period of deinstitutionalisation failed to abolish the spatial differentiation set in place by an initial drive for separate asylum spaces for ‘idiots’ and ‘imbeciles’. Instead, this move all but ghettoised PWLD, as shown by Metzel’s (2005) Baltimore study, leading to a new set of barriers to inclusion within mainstream society. Service provision ‘in the community’ created a new landscape of care which failed specifically to account for the needs of PWLD (Hall, 2007), perhaps creating the ideal conditions for some of the negative associations between home and PWLD evidenced in the following empirical chapters (Chapters 6, 7 and 8).

As a site encompassed by social, cultural and political frameworks, the routine home-space, as outlined within this chapter, is a crucial area for exploration, offering more insight into the mundane, often marginalised, realities of learning disabled lives. Crucially, this chapter has sought to approach the home-space from a learning disabled perspective in order to unpick learning disabled constructions of home as PWLD negotiate a life on the margins. If, as Manzo (2003) suggests, place is entwined within the act of existing, then it is crucial

that this thesis shine light on the ways in which home can help or hinder PWLD in becoming fulfilled, happy and appropriately supported in whichever fashion best suits.

Blunt (2005) has stated that the intimate spaces of the home are both reflected in and acted upon by wider cultural and political scales, and so this claim is taken forward in Chapter 4 with a mapping of the political learning disabled landscape. It is also furthered in Chapters 5,6 and 7 as the thesis explores how these connections manifest in learning disabled interactions with home and community, very much laying bare the myriad ways of being 'at home' for PWLD. The review of the literature offered here has also identified some important subject matters crucial to carry thorough the thesis: the concept of home and the ways in which feeling and emotions are inscribed within that space; neighbouring and the ways in which it impacts on community involvement and feelings of belonging for PWLD; and assumptions of adulthood and the provision of care for those who move from one age bracket to another, and the impact for PWLD. These identified subjects have been drawn out across three main themes around which ideas about home, care and identity continually circulate and, at times, entwine; decision-making, movement and belonging.

The thesis will now turn to the methodological and ethical challenges involved in undertaking research with PWLD, seeking to understand how the historical treatment of PWLD within research feeds into the turbulent realities of home and identity described within this chapter. Furthermore, the following chapter will grapple with the ethical difficulties of research undertaken with those who make their homes outwith the ideal Western notion of home, described here by Blunt and Dowling (2006). Importantly, methods are devised which uncover a learning disabled identity; simultaneously destabilising popular ideologies of home as haven and supporting a feminist critique which

allows, where possible, PWLD to speak about their experiences of dwelling on their own terms.

## Chapter 3

### Research with everyone?

#### Methods for research with people with learning disabilities

This chapter opens with an important discussion about how PWLD are viewed culturally and politically, attempting historically to trace the protectionist attitudes which often prevent PWLD from taking part in research about their lives even now. Here it documents both the Eugenics movement and forms of extreme abuse suffered by PWLD (and others) in the recent past in the name of research, so framing the need for laws which protect potentially ‘vulnerable’<sup>6</sup> research subjects. Moving forward, the chapter tackles the ways in which research has been shaped and challenged in light of protectionist measures by attempting to understand the role of competing models of disability in breaking down barriers. From these questions on how PWLD are seen and represented, the chapter turns to a discussion about enacting contemporary ethical research which accounts for the voice of PWLD without exploiting it. Finally, it turns to the overall funnel structure reflected in the methodological design of the study. This funnel structure is devised to bring attention first to the wider, more generalisable, view of residency for PWLD, and then continually narrows the scope as we learn more about the embodied realities of ‘home’ for a learning disabled individual. By considering the heterogeneous nature of learning disabilities, as well as being aware of disabling discourses which can be reproduced through a lack of communication between PWLD and their wider contexts, this chapter aims to address how the researcher is able to provide appropriate and

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<sup>6</sup> The use of the term ‘vulnerable’ is in itself contentious and not always supported by PWLD themselves.

flexible research which includes and accommodates for PWLD in various ways.

### ***Ways of seeing research with PWLD***

Nind (2008:4) suggests that an overall research design involving PWLD should be based on a thorough questioning of whether research is “for, with or on” PWLD (Nind 2008:4). Power relations between researcher and researched can be problematic and unbalanced, and Nind (2008) argues that this problematic is furthered by traditional qualitative research which tends to treat the ‘subject’ of the study as a homogenous group. Furthermore, Ware (2004) suggests that work *on* PWLD, which does not include or consult them at any stage of the research process, runs the risk of appearing incomplete. Similarly, Chappell (2000) further questions the integrity of research which accounts for PWLD without the people in question controlling at least some part of the research. Drawing from early sociological qualitative work, Kiernan (1999:485) suggests that research should be “cooperative experiential inquiry” where research ‘subjects’ become co-researchers.

This challenge over who should “own and direct” research is essentially political, with Swain *et al* (1999) arguing that research has exploitative potential and Barnes (1996) suggesting that researchers invariably fall into one of two stark camps: oppressor or supporter. Gilbert (2004:298) suggests that the “attitudes of professionals, the diversity and complexity of lay groups, knowledge, power relationships, resources (both personal and financial), and values” continue to impact on the representation of PWLD throughout the research process, arguing that, instead, a move away from “protectionism” would allow a recognition of the “empowering potential” of research which involves PWLD. These protectionist attitudes are not unwarranted and have been constructed amid well-

placed fear for the safety of those with learning (and other) disabilities within any research process.

*A basis for protectionist thinking?*

Even a quick reading of the literature about the recent history of the treatment of PWLD within research throws up a number of examples of horrifying abuse on a large scale, revealing a tendency to ignore the basic wellbeing and agency of those with learning disabilities. It is not surprising, then, to find that the historical practices of many nations have laid the foundations for a sheltering discourse, socially, ethically and within policy, placed around those who could be considered to lack the capacity to consent to take part in research which concerns them.

Towards the end of the nineteenth century, Thomson (2010:117) suggests that a new concern for the health of the general population caused a shift in the discourses surrounding mental disability, resulting in a turn away from philanthropic practices of the enlightenment period. Jenkins (1998:17) argues that this concern grew hand-in-hand with the development and dominance of a statistical measure of normalcy, which simultaneously defined the 'typical' way in which humans 'ought' to be, while clearly demarcating those who were 'below average' and, as a result, potentially dangerous to the health and wellbeing of the general population. Creating this 'model of normal' lent seeming scientific legitimacy to the criterion of adequacy, consequently creating an objective model, at the time "beyond any doubt or reproach" (Jenkins, 1998:18). These scientific tropes echoed those of wider cultural and political thinking, framing a demand for specialised institutional care that would spatially separate those who *could* from those who *could not*.

Asylums of various kind for ‘idiots’ and ‘lunatics’<sup>7</sup> expanded in line with these measures and became increasingly overpopulated by a “long-term population of the chronically sick, incapable and aging”, leading to a mounting concern regarding the links between the problem of mental illness and wider degenerate populations (Bashford and Philips, 2010:117). Anxiety was heightened by a growing belief in the hereditary nature of ‘feeble-mindedness’, making madness and mental deficiency an alleged difficult-to-contain blight on the population, leading to overall cultural disintegration. This construction resonated, both politically and culturally, with a growing international concern about national efficiency in an industrialising and competitive society (Thomson, 2010:119).

Mental deficiency came under particular scrutiny at this time since the condition seemed incurable and, therefore, unmanageable. Moreover, the feeble-minded could easily pass through ‘normal’ society undiscovered and so it was widely believed that the scale of the ‘issue’ was largely unknown: a threatening prospect (Thomson, 2010:119). Thomson (2010:119) also suggests that placing the major social problems of the day on the shoulders of those with mental disabilities provided a “viable target” for theories and anxieties about degeneration which fuelled the fire of eugenic thinking in which “The defective introduced into the population a degenerate, heritable strain, which could manifest itself in crime, pauperism, and immorality.”

Allen (2007:17) believes that embedding biological determinist thinking into cultural and moral discourse provided the perfect backdrop on which the eugenics movement began to thrive, further legitimised by the development of Alfred Binet’s Intelligence Quotient

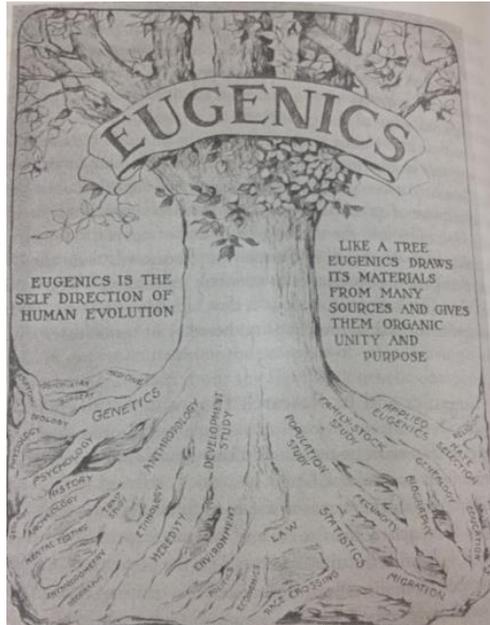
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<sup>7</sup> Roughly paralleling what are now termed PWLD and people with mental health problems.

(IQ test) in 1904, which sought further to classify the 'lazy' from the 'degenerate' (Bartholomew, 2004). Coined by statistician and sometime geographer, Francis Galton, the eugenics movement was most prominent in Western countries such as the United States, Britain and Germany, branding itself as the "science of human improvement by better breeding" (Davenport, 1910 in Nicosia and Huener 2004:17). By bringing together ideas and theories from a number of different fields (figure 2), the eugenics movement claimed that "the most progressive revolution in history could be achieved" (Davenport, 1910 in Nicosia and Huener 2004: 19) by effectively thinking of human breeding through the same pedigree analysis as applied to horse breeding.

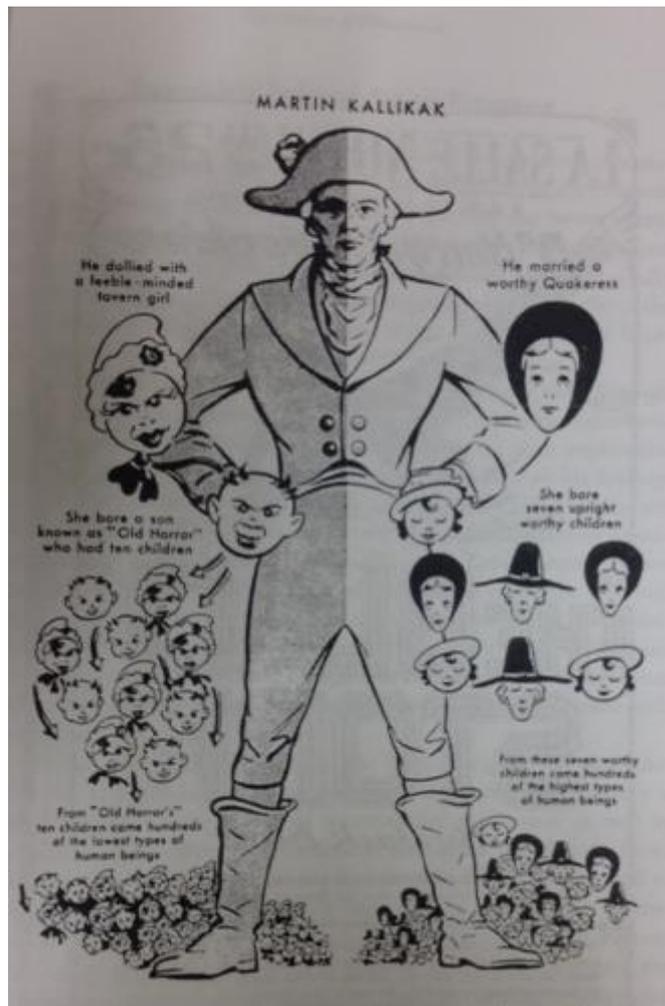
#### *The role of Eugenic thinking in promoting protectionist attitudes*

In addition to research in the field, eugenicists were also keen to promote social action through education, popularisation and changes to policy. Eugenics became part of many school programmes throughout the United States, with the movement heralded as one of the foremost scientific advances of the time and representing the application of rational thinking in solving social problems (Allen, 2007: 22). Casting aside much of the philanthropic work previously undertaken, it was becoming widely accepted that alcoholism, feeble-mindedness and pauperism, among other dysgenic qualities, were a result of bad genes which should not be encouraged to survive (Allen, 2007: 22). Seeking to promote the virtues of eugenics as widely as possible, propaganda surrounding the issue grew, such as that evidenced in figure 3. Drawing on the Kallikak study by Henry H. Goddard (1912), the image outlines the hereditarian principles of 'good' and 'bad' breeding, each side representing the outcome of 'dallying' with a "feeble-minded tavern girl" over marrying a "worthy Quakeress" (Allen, 2007:23).



**Figure 2.** Showing the multi-disciplinary nature of the Eugenics movement which gave it 'credence' amongst scientists of the day. (Source: Allen, 2007:18).

Through such propaganda, eugenicists were instrumental in bringing about compulsory sterilisation laws, allowing for those residing within institutions (including asylums and mental hospitals) to be “forcibly sterilized” upon examination from a eugenics committee and a meeting with relatives of inmates (Allen 2007: 28). “[L]ow moral sense” and “hereditary feeble-mindedness” were among many categories which could lead to forced sterilisation, using eugenics as a sound scientific basis from which such decisions could be made. Such schemes were not without contestation, but Allen (2007: 29) argues that those opposed to the principles of eugenics did not have the same appeal since this stance failed to provide alternatives to ‘fixing’ a wider social degeneracy that eugenics promised to eliminate.



**Figure 3.** Cartoon depiction of Kallikak study by Goddard (1912) in Nicosia and Huener, 2008:23

Although clearly not alone in acclaiming eugenic cleansing, Nazi Germany provided perhaps the most extensive “ambitious and far-reaching experiment in eugenics ever attempted by any nation” (Allen 2007: 33). Having existed in the form of the *Gesellschaft für Rassenhygiene* (Society for Racial Hygiene) since 1905, legitimising eugenics through legislative change began to take centre-stage in German policy with the rise of the Nazi regime (Allen, 2007:32; Thomson, 2010: 121). Drawing on principles outlined in Laughlin’s “model sterilisation law”, which outlined legal parameters for the nation-wide sterilisation of the “socially inadequate” (Laughlin, 1922), Nazi Germany developed and established its own legal practices for involuntary sterilisation which saw the sterilisation of over 400, 000

individuals with “feble-mindedness”, “epilepsy”, “deafness” and “serious alcoholism”, among many others. Furthering this, the Nuremberg Laws passed in 1935 (Allen, 2007:33) forbade the marriage of “Aryans” to anyone with more than one quarter Jewish descent, so symbolising the widening eugenic framework incorporated into a very specific discourse of normalcy. Although internationally criticised for the passing of such laws, the Nazis responded by pointing out similar anti-miscegenation laws in America as well as in other countries (Allen, 2007: 33).

Allen (2007: 33) and Thomson (2010:121) posit that the scope of the eugenics movement was exaggerated in Nazi Germany given the “severe economic and social constraints under which Germany laboured in the interwar period”. Among other reasons, the degeneracy of the German population was offered as a reason why the country had been defeated in WW1, emphasising the need for the government to interfere in order to “strengthen the hereditary health of the nation” (Allen, 2007: 33) through the implementation of relevant, radical, eugenic policy. Moreover, the cost of caring for the “socially inadequate”(Allen, 2007: 33), eugenicists argued, was economically detrimental to the state, building a strong case for the elimination of “non-productive eaters” (Allen 2007: 34). Eugenics provided the scientific validation for drastic cuts to the “social welfare, health care, and institutional programmes for the old, the indigent, and those thought to be genetically handicapped” (Allen, 2007:34).

In Seidelman’s (2008:98) essay on the pathology of memory, he talks about the horrific realities of the eugenics movement for those lives which were deemed worthless. Under the eugenics sterilisation programmes rolled out across Germany, all newborn handicapped children were registered with the state and therefore entered into a programme for “intentional killing”. Within mental asylums, paediatric wards known as *Kinderfachabteilungen* were established.

Here children could be killed through high doses of medication, such as Phenobarbital, or alternatively by deliberate starvation in “hunger houses” (Seidelman, 2008: 98). A leader in this field, Professor Carl Schneider of the University of Heidelberg, performed psychological studies on those children who were destined to die in such ways, the brains of these children being removed for further study after death. Seidelman (2008: 98) argues that many prominent professors and researchers of the time exploited euthanasia killing programmes in order to benefit their research, without any trace of concern for the wellbeing of patients, clearly the seed from which ethical concerns regarding research with PWLD has subsequently grown. While involved with the paediatric ‘care’ of mentally disabled children at the *Nervinklinik für Kinder* in Vienna, Dr. Heinrich Gross conducted several extremely invasive experiments on patients. One such experiment included subjecting children to a pneumoencephalogram, an extremely painful procedure in which cerebral fluid is removed by lumbar puncture, and replaced by air, allowing the structure of the brain to become more pronounced under X-ray (Seidelman 2008: 102).

These forms of eugenic extremity were not uncommon within Western nations; however, in the shadow of WW2, eugenic thinking became a stigma associated with the irrationality and cruelty of the Nazi regime, building on a mounting scientific critique which denounced eugenic discourse (Thomson, 2010: 124). This is not to say that some nations did not continue to promote the sterilisation of the feeble-minded; indeed, Canada, Denmark, Finland and Norway continued until the mid-1970s (Thomson: 2010:125). It could be said that contemporary protectionist attitudes have grown from an uncomfortable proximity to this eugenic legacy. In particular, the establishment of legislative reform in the shape of the Declaration of

Helsinki (1964)<sup>8</sup> arose as a result of the human rights violations carried out in Nazi Germany, and elsewhere, in the name of scientific research. Outlining best practice within medical research, the Declaration of Helsinki answered a call for a definitive outline of acceptable international standards in all areas of medicine (Ashcroft, 2011:141). The declaration is not without criticism, and has undergone many reforms, but it remains a central international guidance document in the formation of laws which govern ethical medical research, ensuring that, as far as possible, eugenic abuses such as those witnessed previously could never happen again.

How disability is viewed has also changed, with wide if not universal recognition that people with learning disabilities have the same right to the life of their choosing as people who are not considered disabled. The protective arm that society now places around those with disabilities, both culturally and through policy, has perhaps perpetuated an intimation of childlike innocence to those with learning disabilities, which Jenkins (1998:16) argues remains current (at least at the time of writing his paper). While it is obvious that research should never again be allowed to take precedence over the mental and physical wellbeing of participants, as shown clearly by the horrors of eugenic thinking, learning disabled or otherwise, it is problematic to suggest that the alternative is never to include PWLD within research. Wolpert (1978) suggests that, like others without

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<sup>8</sup> Created by the World Medical Association, the Declaration of Helsinki (1964) is a code of ethical practice for clinical research. Developed in replacement of the Nazi associated Nuremberg Code (1947) it provides international guidance on human experimentation (Goodyear *et al*, 2007) but has not been without critique. Its focus on first world ethical practice has not passed without comment and Angell (1988:1081) notes the declaration's "ethical Imperialism", particularly in relation to the treatment of AIDS in sub-Saharan Africa. Moreover, Goodyear *et al* (2007) argue that the declaration often protects the efficiency of research at the expense of the human subject. In an ethical landscape of conflicting research guidance from Unesco and the Council for International Organisations of Medical Sciences, Lei *et al* (2004), among others, have questioned the relevance of the declaration itself. Nonetheless the Declaration of Helsinki remains the foremost influential document regarding research ethics.

disabilities, learning-disabled participants within research should be afforded the dignity of risk in taking part in research, allowing a degree of agency in the decision-making process, albeit perhaps with help from the non-learning disabled support networks around them. Such procedures as those described above makes it easy to see why research with both children and those with disabilities are so rigorously mediated by ethics committees and researchers alike, and lends weight to the importance of considering how academics approach research on and with PWLD.

### ***Approaching research with PWLD***

One way in which research has shifted to account for protectionist discourses in how researchers interact with those with learning disabilities is through the establishment of new methodological approaches. Within this changing environment there are many different views on why this group have continued to be excluded from the research process. Clements *et al* (1999:106) believe that there are two opposing social pressures which continue to influence how research is conducted: the liberal social agenda and the rise of “the cleansing elites”. The liberal social agenda is said to be trying to “put people first”, driving for greater respect for people labelled ‘disabled’, but Clements *et al* (1999) suggest that these social advances have not crossed into the field of research in order to enact change in how people with a range of disabilities are studied and ‘used’ within research. Moreover, some, such as Oliver (1992), have suggested that social research is viewed by many disabled people as a “violation of their experience” rather than a challenge to their “devaluation and dehumanisation”; and, as such, research should be led by the researched rather than the researcher in order to affect social and/or political change (Clements, 1999:106).

### *From medical to social models of disability*

This shift from medical to social modes of research is one which has been echoed in wider socio-political discourse surrounding the rights and identity of those with a range of disabilities. In the last three decades, some people with disabilities have begun to challenge ‘disabling discourse’, seeking to alter over-medicalised and individualist accounts of disability (Shakespeare, 1998)<sup>9</sup>. By concentrating on the social oppression, cultural discourse and environmental barriers which hinder those with disabilities on a daily basis, the movement has rejected medical accounts of disability as a biological deficit. Emerging from the political force of the *Union of Physically Impaired against Segregation* (UPIAS), the social model in Britain sought a distinction between ‘disability’ and ‘impairment’, claiming that ‘impairment’ is a private matter, whereas ‘disability’ is a social construct (Shakespeare, 1998). Drawing parallels with the feminist stance on biological sex versus gender, Shakespeare (2013) argues that, like gender, disability could be considered a “historically specific phenomenon, not a universal and unchanging essence”.

Moreover, the social model challenges the power of medical practice to describe disability in terms of “personal tragedy”, instead recognising the “externally imposed restrictions” (Oliver 2004:19) which diminish the complexity of everyday disabled lives to issues of “medical prevention, cure or rehabilitation” (Shakespeare, 1998). By embracing the social model, some people with disabilities have sought to use civil rights as a means of ending the social oppression faced when dealing with organisations run by non-disabled individuals. This distinction between disabled and non-disabled is essential, since it is argued that organisations and services run for and by those with

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<sup>9</sup> See papers by Briesenden (1986), Fisher and Goodley (2007) and Areheart (2008) for further commentary on the medical model of disability.

disabilities provide the most appropriate solutions to real world issues (Shakespeare, 1998).

While the social model has ignited debate around the social and political constructions of disabled identity, there are a number of ways in which it has been critiqued. Shakespeare (1998) argues that the simplicity of the social model has ultimately become its downfall, since it not only fails to account for the complexity of individual experience, but is also authored in the majority by white, heterosexual males who became disabled at some point throughout the life-course, therefore not representing the experiences of most disabled individuals. PWLD are weakly represented in debates about the social model, and indeed in political movements for disability rights (which follow from accepting tenets of the social model), representing an issue which is to do with their perceived cognitive 'limits' of being able to engage in conceptual discourse and political engagement. Most notably for my own research, the model has failed to become a catalyst for change amongst those with learning disabilities given their limited access to the fields in which much theory is developed. Crow (1992:7), in particular, argues that, instead of renouncing the corporeal difficulties which she faces day-to-day, an alternative model must be found which "integrate[s] [disabilities] into our [disabled individual's] whole experience and identity", as such promoting "physical and emotional well-being". By so strongly disowning individualistic approaches to thinking about disability, the social model can be said to be 'glossing over' the embodied realities of impairment. Furthermore, Bury (1997:137) argues that "reduction of barriers to participation does not amount to abolishing disability as a whole".

This notion is taken yet further by Thomas (1999), who argues that the social model of disability speaks only to a structural disablism, which focusses on barriers such as employment, inaccessible information

and workplace discrimination, not the deeply personal, psycho-emotional disablism, which entails the disabling impact of stigma, bullying and internalised oppression. Reeve (2012) points out that social models of disability may not deny the existence of psycho-emotional impacts but, as Thomas (1999:46) argues, they fail to recognise more than just “‘barriers’ to ‘doing’” and rather should strive to understand “‘barriers’ to ‘being’”. Thomas’ (1999:46) critique of materialism is not to bolster the notion of disability as ‘medical tragedy’ but instead to highlight the psycho-emotional as a dimension of disablism which arises from “oppressive social relationships”. This progresses a social model of disability which focuses on ‘restriction of action’, recognising those actions which also limit psycho-emotional wellbeing by making those with learning disabilities feel “worthless, of lesser value, unattractive, hopeless, stressed or insecure” (Thomas 1999:47). Thomas (1999:48) is keen to stress that this is not a simple reframing of disabled people as “passive recipients or victims of disablism”, but instead highlights the ability of PWLD to exercise agency or be complicit in acts of resistance, even at the personal level. This is a critical underpinning of this thesis as it attempts to uncover the interplay between the personal, political and cultural experiences of ‘home’ and a learning disabled individual.

#### *Bio-social model of disability*

In attributing the body as a site capable of representation, Hall (2000) extends work by McDowell and Court (1994), Bell and Valentine (1995), Pile and Thrift (1995), and Thomas (1999), looking beyond the stark social/medical binary of body politics critiqued by Crow (1992). Recognising Parr’s (1998) concerns about the neglect of the physical body in geographical work, Hall (2000) suggests a renewed socio-biological understanding of the body in which history, culture and politics are recognised as both acted upon, and made from, relationships between other bodies and spaces. Rejecting the

“individual pathology of disability” (Imrie 1996), while simultaneously recognising its potential to obstruct, Hall (2000:24) suggests that a socio-biological model can shed light on the learning disabled body (and mind) as an “embodied and material” whole, both personal and social. This way of seeing disabled lives lends itself to a methodology which works towards the representation of PWLD from *their* perspective and in *their* words, allowing learning disabled participants to recognise the alternative ways in which they use the spaces and places around them and further negotiate the social, cultural and environmental idiosyncrasies which represent their embodied experience of learning disabled residential decision-making, movement and belonging.

Like other forms of identity politics, the disability rights movement has sought change in how disabled people are imagined, known and therefore treated within society. Unlike other rights movements, such as those based on sexual orientation, Shakespeare (1998) argues that removing social discrimination levelled at those with disabilities will not remove the “intrinsic limitations” presented by the “obdurate realities” (Redley, 2012) of being physically or mentally disabled, and so those with disabilities will remain disadvantaged to some extent.

Admittedly, the approach to impairment of the social model lacks the personal, perhaps mundane, look at everyday learning disabled interaction which is the point of interest for my study, but can be useful as a tool with which to reject the homogeneity of the medical model when researching with PWLD and disabilities in general.

#### *Competing paradigms of disability research*

Within research, the rights of those with disabilities has emerged as two competing paradigms, each seeking to conduct and create research which is both fair and accessible. Gilbert (2004:299) notes that each “promote[s] a particular philosophical or ethical position”,

each aiming to understand further the relationship between PWLD, others and their environments: participatory research and emancipatory research (see Table, 1). Both of these perspectives are socially motivated, but participatory research is questionably critiqued for clinging to 'normative ideals', whereby difference is seen as deviance, and so is maintained within an ongoing cycle of stigma and social exclusion. Emancipatory research, on the other hand, is said to be drawn from the social model of disability and, as such, aims to catalyse political change through the research process.

Essentially, Gilbert (2004:300) argues that the distinction between participatory and emancipatory research lies in the decision over who is in control of the research process. Through participatory approaches, the researcher collaborates with participants using qualitative methods which extract answers to a specific question set by the researcher. Conversely, emancipatory research is said to allow the participants to use the expertise of the researcher to initiate research in areas of importance to them, effectively changing the relationship between researcher and researched. The ties between emancipatory research and the social model of disability, however, still leave it open to many of the same criticisms levelled at the social model. Atkinson (1997) and Gilbert (2004:300) point out that, while control of the research process for PWLDs is an ideal, the reality of achieving this ideal is less likely considering that participants may have "little or no access to either the written or spoken word", and so suggests instead an alliance between PWLD and "sympathetic non-learning-disabled people" around them.

Within academic Geography, distinctions between both terms (participatory and emancipatory) is not so keenly recognised, the research following these paradigms aligning more with Walmsley's (2001:187) call for "inclusive research", denoting a range of methods which straddle participatory and emancipatory approaches. On the

subject of learning disability, however, the differences between the two opens space for crucial discussion on how research with PWLD is viewed and conducted. In order for research to be truly emancipatory, Barnes (1992) argues that researchers must devise ways in which they can use their knowledge and skill *on behalf* of those with learning disabilities. Zarb (1992) takes this point further still, arguing that the emancipatory paradigm can only be ascribed to research which is fully devised, controlled and carried out by PWLD, free from any non-learning disabled intervention. So, while geographers may flit between both terms interchangeably, it is critical within the learning disability field to pay attention to the points at which these terms deviate. Usefully, Stalker (1998:6) suggests that they share three core beliefs: recognition of the researcher/researched power imbalance; the right of PWLD to be consulted and included in research which discusses them; and the ability of participation by PWLD to strengthen the research process and to make outputs more relevant. Gilbert (2004) suggests that this core then highlights a bridging point between each approach, whereby some aspects of each might be usefully employed within research with PWLD. Walmsley (2004 in Nind 2008:5) suggests that, through support of 'inclusive' research methods which work between emancipatory and participatory methods, research can be co-produced<sup>10</sup> in order best to reflect the lived experience of being considered learning disabled.

Emancipatory research is perhaps a step too far for some researchers, and so Burke *et al* (2003:66) suggest that participatory research can be a useful step along the way for both the researcher and those who have previously lacked "experience, confidence or control" of resources which may enable them to 'speak' about their own lives.

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<sup>10</sup>The theme for the whole RGS-IBG Annual Conference (2015).

Participatory Research	Emancipatory Research
Based on normalisation theory	Based on the social model of disability
Interpreting and explaining the experiences of those with learning disabilities	Changing the condition of the relationship between researcher/researched
Relies on qualitative methods	Relies on a mixture of qualitative and quantitative methods.
PWLD participate but are not in control of the research	PWLD have full control over the research process
Partnership between the person with learning disabilities and a (often) non-disabled researcher	Researcher's expertise are at the disposal of PWLD
Researcher remains accountable to a funding body	Researcher accountable to person with learning disabilities

**Table 1.** Showing a linear example of the core differences between participatory and emancipatory research as recognised in the learning disabled research field (Gilbert, 2004).

While my research does not seek directly to change the lives of the individuals within the study, this does not mean, as Clements *et al* (1999) controversially suggests, that I am effectively abusing my position as 'researcher'. I would argue that an in-depth understanding of 'home' spaces for PWLD could provide a basis for change in how home is understood, thought about and decided upon in the future for PWLD and their family or carers. There is a certain brash authoritarianism in suggesting that all research *must* achieve change, which ignores that sometimes simply giving PWLD voice and taking PWLD seriously are also entirely valid, perhaps even emancipatory, gestures (Hall, 2004). Like Gleeson's (2000:65) discussion on 'enabling geographies', I see this work as contributing something positive to the corpus of work on learning disability which goes some way to addressing the power balance between researcher and researched (Oliver, 1992), giving further light to the complexity of learning disabled lives (Kitchen, 2000; Hall 2004). Chouinard (2000) has called for a radical geography of empowerment, while Askins (2011;2008)

speaks of participatory action research in which power relationships are meaningfully disturbed by the research process with the intention of laying clear tensions, so leading to the production of new knowledge regarding the lives of minority groups, like those with learning disabilities. Within this research I hence wish to occupy Rose's (1997:313) space of "betweenness", where researchers "claim neither a distanced objectivity nor sameness" (Worth, 2008:309), instead situating themselves on "shared analytical ground" with those with learning disabilities. As such, I would place my own research more within the participatory paradigm, using specifically chosen and adapted methods to allow the experience of the research process to be as inclusive as possible within the acknowledged time, financial and ethical constraints of PhD research and funding, as acknowledged by Kitchin and Wilton (2000).

### ***A question of ethics***

As with any research project, it is important not only to consider how the research should be approached, but also the ethical considerations which must accompany it, something particularly relevant when conducting research with PWLD. Reflecting on earlier discussions addressing the historical treatment of those with learning disabilities within research, it is important to recognise the "need to protect vulnerable participant groups", while at the same time ensuring that the demands placed on the researcher "are not so restrictive as to preclude valuable research" (Iacono and Murray 2003:49). Furthermore, it is important to be aware that being more involved in research with/about PWLD may not make them less vulnerable to the impacts of research. Some common sense is required, however, and we must also question how ethical it would be to exclude PWLD from research which could "provide insight into their experiences and help to shape" and change their future (Nind

2008:6); effectively denying them access to that 'risk', as Wolpert (1978) might suggest.

### *Consent and learning disability research*

McDonald and Kidney (2012) recognise that, in rectifying the abuses of the past, research with PWLD has become more conservative and so less fit for purpose, leading to problematic access to research deemed 'too risky' both for PWLD and researchers. Those concerns range from perceived vulnerability to coercion (Cambridge and Forrester, 2003) and perceived inability to weigh up the risks of the research undertaken (Aman and Handen, 2006), to concerns over systematic exclusion of those with learning disabilities (Diesfeld, 1999). In short, the research may speak to PWLD but not on subjects about which they may feel passionate or vulnerable, and yet researchers must also never fail to include them in the same way as the rest of the researchable population. This research was conducted precisely within these protectionist tensions, walking the line between protectionist attitudes which seek to protect PWLD from any difficulty or challenge in the research process, and an attempt genuinely to secure their participation and possible co-production of knowledge about their lives. It was precisely this attempt to exclude PWLD from potentially 'risky' situations which characterised a difficult route through the ethical procedures associated with the research.

Nind (2008) also highlights issues surrounding the 'research relationship', pointing out the ethical importance of negotiating terms of engagement (Walmsley 2004:65) which focus on how "rapport is established and boundaries maintained". When using the home as the site of research, Stalker (1998) warns that sensitivity to the role of the researcher must be addressed, since their position is easily construed as intrusive or misconstrued as friendship. The researcher must also be aware that interaction could potentially widen a participant's

normal social circles, and so has to understand the impact that this could have after the research period, when perhaps that circle narrows again. Furthermore, Stalker (1998:10) points out that the researcher can become one face among many, drifting in and out of people's lives, entirely outwith their own control.

Central to ethical considerations is the notion of informed consent. Scott *et al* (2006:277) highlight three key issues: "the person's competence to give consent, the extent to which the research is in the person's own best interests and the balance with public interest". Historically, PWLD were not legally considered able to consent, but this notion has changed, and in legal terms a person is now considered competent, "not when a certain age is reached but when he or she 'achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed' and has 'sufficient discretion to enable him or her to make a wise choice in his or her own interests'" (Morrow and Richards, 1996:96), albeit potentially still an exclusionary premise.

#### *Competency and learning disability research*

This issue of participant competency, or rather *incompetency*, is one which is questioned throughout the research process, but can be difficult to define and hard to establish. It is therefore important to consider why adults with learning disabilities may be assumed incompetent. Jenkins (1998:11) speaks of 'models of incompetence', arguing that competence is a socially, culturally and medically constructed phenomena which, despite its ties to scientific rigour, can never be considered homogeneous. Furthermore, Jenkins (2008:3) suggests that PWLD are considered to be incompetent since they are entangled within other 'domains' of classification from which the meaning of vulnerability is derived: age and life-course. Like PWLD, children are also viewed as less competent than 'normal' adults since

they are “imperfectly socialised and psycho-socially immature” (Jenkins, 2008:3); but, unlike those with learning disabilities, children are presumed to be on their way to competence. Conversely, a lack of speech, loss of mobility, diminished independence and/or memory loss within the elderly is considered to be a normal part of growing old, which implies a previous state of competency. Learning disability has been referred to as a developmental disability precisely because some individuals are seen not to ‘develop’ properly along this pathway of competence (Simpson, 2004). Jenkins (2008) argues that these discourses around the understanding of vulnerability spill over into how people with learning disabilities are thought of, treated and protected by society. In ‘protecting’ this vulnerable group from the harsh realities of life, Jenkins (2008:123-124) argues that PWLD have also been stripped of their right to an “autonomous reflexive individual self” which manifests in who is considered competent to participate in research.

These protective discourses unquestionably serve a purpose when considering the treatment of some PWLD under the guise of research, but Jenkins (2008) warns against homogenising a highly diverse group of individuals. Assuming that all PWLD are incompetent is no more fruitful than assuming that all people are competent, and it is important that the label ‘learning disabled’ does not preclude PWLD from taking part in research *before* alternative means of understanding have been fully explored. Expanding on this point, Angrosino (in Jenkins, 2008:5) would argue that those with learning disabilities are not incompetent because of what they do not know, since that is an inherent part of all individuals, but rather that their social interactions involve communication of a different kind, in which researchers are sometimes incapable or unwilling to partake. The term ‘learning disability’ arguably tells us no more, or less about the person we are to interview than knowing their gender. Arguably, the

label should merely be used as a sign to researchers that they must look to change the modes through which they discuss, create, investigate and share knowledge during the research process.

### ***Enacting ethical research***

As such, the ways in which the requisite understanding and intelligence is measured may reflect more on how the research is put forward than a participant's capacity to understand it. Since capacity to give informed consent may be impaired by communication difficulties or issues with memory, problem-solving and expression (to name but a few), Dunn *et al* (2006) use methods of simplification, delivering the same information in different formats in order to ensure that it is accessible. Tying in with the current personalisation agenda within policy, Harris (2003:5) further argues that social and environmental factors also require consideration when researching with PWLD, since many live in situations where choice decisions are made partly by someone else (if not fully), again a key consideration of this research. However, Harris (2003) argues these definitions of choice depend on the person doing the choosing being aware that "at least two options for action exist" and that "he or she can influence which option is chosen", something potentially problematic when considering research with PWLD since participants may not be used to being asked, nor having their responses taken seriously.

Furthermore, choice can similarly be restricted if PWLD do not have the means to indicate their choice. This is particularly problematic where people have communication problems, and so have few opportunities to make decisions or, alternatively, have previous experience of negative impacts when making choices. Harris (2003:4) argues that "in a variety of social situations, options are available, but choice is restricted by conventions and social expectations". Choice, as an internal mental process, causes concern over the capacity of

PWLD to make decisions, with Turnbull (1975-1976 in Harris 2003:4) arguing that consent can only be obtained if a person has: “appropriate and sufficient information”; the capacity to understand consequences; and can “give their consent freely”. Given these parameters, it is not surprising that most PWLD are deemed unable to give consent. Many assumptions on capacity assume that participants must follow an idealised thought process; however, Harris (2003:5) argues that there is nothing to suggest that these processes are carried out in most ‘ordinary’, day-to-day decision-making by all of ‘us’. Furthermore, this ideal framework refers to an ‘intellectual capacity’ which fails to recognise social or environmental factors as key to decision-making; a crucial consideration which is central to the research project at hand. As such, Nind (2008:7) wishes to go beyond “just re-presenting information” in other formats, to recognise that information may need to be “absorbed over time with an understanding reached in ‘the doing’”.

Nind (2008:7) further suggests that some PWLD often fear the consequences of choosing and feels that formalised consent tends to neglect the fleshy reality of the learning disabled experience, since:

[it]is based on an idealized sequence of mental activities in which it is assumed the person: receives information; retains it; considers the options; considers the implication of each option; considers the implication of not deciding; makes a decision (mentally); and communicates that decision to other people.

Harris argues that this sequence has very little bearing on how the decision process is experienced for PWLD or, indeed, any non-disabled person. Nind (2008:7) proposes that, while formal decision-making is based on “individual psychological processes”, it could instead be understood from a sociological point of view which understands choice in “relation to social practices and shared meanings”, again a key facet of the empirical research being carried out. Harris points out that, if people are consistently left out of the choosing process, such

as in the case of some PWLD, then they begin to see themselves as powerless and unable to contribute to the outcomes of decision-making. This thinking can be promoted within situations which are not properly structured to support choice. Through “highlighting the functional relationship between a choice and its consequences” and by “enhancing the capacity” of PWLD to signal choice, there is no reason why PWLD cannot be consulted about choices within research situations. Respondents with learning disabilities must also be made aware that expressing a negative or alternative view is not something punishable, but instead is valued by the researcher. While families and carers can help to facilitate ‘discussion’ with PWLD, the researcher must also be aware that they can be hindrance if the respondent perceives a negative reaction to the choices made. This issue is particularly significant within this research, since families and carers may also be the dominant force in residential decision-making.

In order to enhance the capacity of PWLD to give informed consent to the research process, researchers must be aware of better modes of communication which perhaps differ from ‘traditional’ consent gaining methods. Gilbert (2004:304) suggests that initial contact with possible participants should promote a trusting and engaging research environment, which recognises the heterogeneity of their communication needs. Both Cameron and Murphy (2007) and Cambridge and Forrester-Jones (2010) have used illustrated summary letters, formed using Mencap’s accessible language principle<sup>11</sup>, as well as explaining to potential participants and their carers who then ‘translated’ gestures of willingness to participate (or not). As well as

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<sup>11</sup> Together with PWLD and their families, Mencap continue to update and circulate information which offers help and guidance on making written information for PWLD more accessible. By following basic principles, such as using larger font and writing in shorter, less complicated sentences, those with learning disabilities can be helped to access a variety of information in a format which they can better understand. This opens up possibilities for involvement of more PWLD in matters which concern them (<http://www.accessibleinfo.co.uk/pdfs/Making-Myself-Clear.pdf>).

this, they gave repeated explanations to participants, leaving them as much time as they needed to take in the information. This repetition was achieved with help from carers/family members, and Walmsley (2004:60) argues that there is “unlikely to be a substitute for working alongside people who know the individual well and can draw on the experience of what works with him or her”. Nind (2008:8) adds that it is often family members who can best understand individual idiosyncrasies which may be vital to the research conversation. Consent can also be gained through consent networks, and Icono and Murray (2003:43) maintain that this tactic helps “decisional capacity”, although they also warn that power relationships within their networks can come into play and threaten the voluntary nature of decision-making. Furthermore, Cameron and Murphy (2007:44) suggest that support/care workers or family members can, without ill-meaning, coerce relatives into participation, and therefore it is important to be alert to this possibility and to collect and report on “non-participation data”, which shows that consent procedures are working and there are no compliance issues.

Ware (2004:177) adds to the debate on the use of carer/family member ‘interpreters’ during the consent and research process, suggesting that proxies can have a positive impact on the quality of life for the individual, while also noting that the ‘reading’ of others’ expressions requires a high degree of inference and, as such, cannot be considered exact in any way. Studies by Green *et al* (1990 in Ware 2004:177) have shown that different adults can interpret the same behaviours differently, and so Ware suggests that researchers must constantly review their interpretation of learning disabled behaviour (in this instance) and, moreover, be aware that sometimes they may judge wrongly. Clements *et al* (1999) flag up the issue of “acquiescent responding” whereby respondents may agree for other reasons, even when they are fully able to understand the questions posed. Williams

(2011:51) terms these 'grey areas', "neither good nor bad, but just plain difficult". It is therefore essential that researchers develop and establish new and adequate methodologies which work with PWLD and their families/carers to create research environments suitable for everyone involved. As such, it is crucial to my research to ensure that multiple and fluid research methods are in place which best suit a respondent's individual needs and, moreover, to recognise that I owe them these considerations for the time and effort that they are putting in to my research.

#### *Communication in the research process*

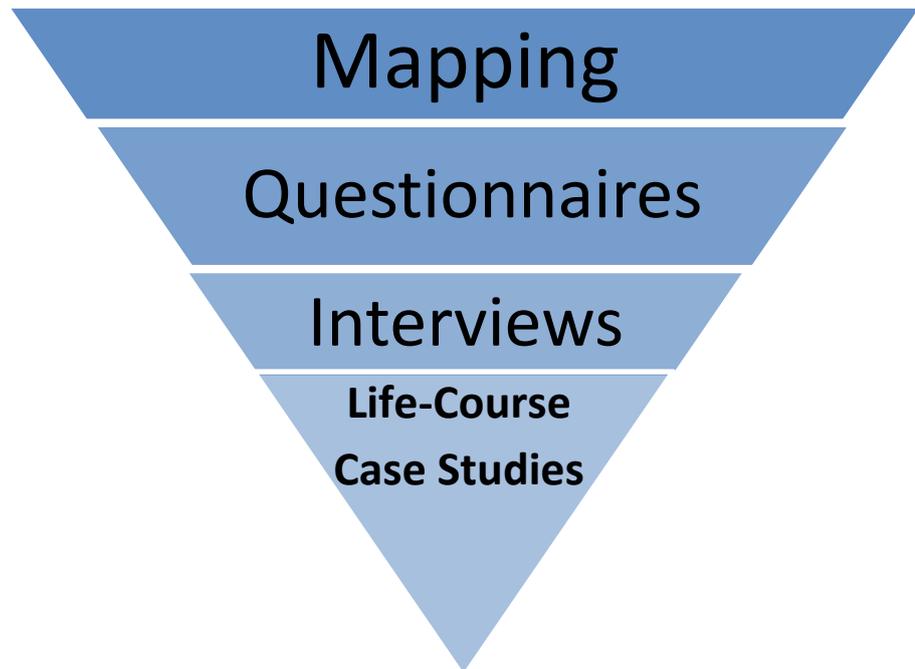
Clements *et al* (1999:110) suggest that those with learning disabilities (in my case) need a place within the construction of research in order that their voices are heard throughout every stage of the research process. Within my own research this outcome could have perhaps been achieved by initiating discussion between parents, carers and interested groups in order to develop plain language information and research strategies suitable for an array of learning disabilities, as used by Cameron and Murphy (2007). This process would have meant that the same information was reproduced in a number of ways (including the use of visuals and graphics) to represent as wide a group as possible, allowing respondents the opportunity to choose a method of inquiry which best suits their needs. It would go some way towards meeting Clements *et al's* (1999:110) claim that researchers and academics need to "learn better communication skills". Additionally, Clements *et al* (1999:110) discuss "respect for persons", further covering aspects of consent and arguing that the term requires "refinement" so that it becomes a continual consent process rather than a one off event. This continual process of consent from the person (rather than the institution) is highly relevant to my research, having chosen to re-work my communication methods to suit each individual and sometimes requiring several visits rather than a one-

off. Cambridge and Forrester-Jones (2003:10) also include, within the consent form, pictures of potential researchers in order to add a visual element to the process of consent, allowing respondents to begin to judge whether they wished to work with the person conducting the research. This practice was an excellent and simple way to begin to personalise the research experience before interviews begun, allowing respondents to begin the process of getting to know me, the researcher, and an important step towards creating a trusting and safe research environment. The stringent ethical procedures through which this research passed, did not allow for the intended co-production to move forward as planned, discussed later in the chapter but many of the visual elements remained, opening up much needed routes of access to research.

### ***Research design***

It was important that these 'learning disability friendly' research techniques were carried forward into the design of the study itself, ensuring that it identified the individuality of respondents; highlighting their abilities as opposed to their disabilities. The work should also recognise the different spatial scales through which learning disabilities can be viewed and understood. Reflecting this, the research takes on a funnel structure, which deliberately encapsulates both general trends, with a wide spatial optic, and individual experience, highly localised. From a more general mapping of where PWLD currently live, the methodological focus hence narrows to explore the smaller, private spaces of learning disabled life which are often overlooked. Applying this funnel structure serves as a reminder that in-depth, personal experiences are inextricably bound within wider social, environmental, cultural and political contexts and discourse, affecting individuals in varying ways, at different scales. Forthwith, this chapter will discuss how the research can be carried out in a way which best reflects the need of respondents through a

process of mapping, questionnaire work, interviews and case-studies (see figure 4 below), each of which can be understood as phases which feed one part of the study into the next. Naturally, such work requires ethical approval and this study has not been without its complications, something I will address towards the end of the chapter.



**Figure 4.** Showing the methodological funnel structure of the thesis.

### *Mapping*

Phase one of the research involved a general mapping of where PWLD live within the Greater Glasgow and Clyde (GG&C) area. Random samples of 2000 postcodes were provided by the Learning Disabilities Liaison Team of NHS Greater Glasgow and Clyde, listing adults within this area who have been identified as having a learning disability by their GP. Although perhaps not wholly representative, it provided enough information to establish general trends in the data. The information contained postcodes, gender and age only, and so the researcher was unable to link this data to any personal information which may have led to the identification of individuals. Using MapInfo Professional 11.0, several maps were created, usefully outlining the

boundaries in which the GG&C area can be found, and highlighting those postcodes which show the largest learning disabled populations in need of further investigation.

By looking still more closely at portions of the map, distribution of PWLD within postcodes was more obvious and so the maps could be used as an analytical tool to discover more about the types of residency in which some PWLD were living. By then using the Google search engine the types of residency represented could be uncovered, for example identifying group homes or private residencies. Moreover, the maps could be used to make inferences regarding factors influencing residential locational decisions such as proximity to services, types of accommodation and possible implications, for example socio-economic status of the neighbourhood.

Mapping has been a useful exercise in allowing a broad understanding of the area represented by GG&C and its overall patterns of learning disabled residence. This exercise in turn allowed questions regarding the data to arise *from* the data rather than being imposed from without, therefore feeding directly into the questionnaire phase of the research which seeks to understand more about these patterns, adding a feeling of flow to the otherwise static nature of the maps. Engaging with and exploring the database in this way revealed the different residential situations of those within the GG&C sample, giving some impression of the specific environments and neighbourhoods in which they live. The results produced through this method are discussed in more detail in Chapter 4.

### *Questionnaires*

The use of questionnaires is a potentially problematic method when considering working with PWLD, since the basic principles of a questionnaire (unless face-to-face) requires that it is written. Again, there is a need to think beyond written representations of opinion in

order best to bring forth the information required. The questionnaire itself for my own research was designed in such a way that at least encouraged those with learning disabilities both to engage with the research and attempt to answer the questions asked. Moreover, respondents were made aware that help could be given by significant others, carers, support workers or indeed in face-to-face interaction with the researcher – an offer taken up by two respondents. McConkey and Mezza (2001) outline the success of one such study where support workers answered questionnaires in conjunction with the respondent, although this approach has obvious validity issues. Nind (2008:12) uses the example of an inclusive research project run by Liverpool Heritage wherein respondents were given the opportunity to reply through text or imagery. The use of images and alternative communication forms is again exemplified by Cambridge and Forrester-Jones (2003) in their ‘total communication framework’, briefly mentioned earlier this framework centres around the provision of alternative and inclusive modes of communication which can be provided on an individual basis and therefore altered to suit the specific needs of the individual. This framework was something that I considered for my own research, although the net could have perhaps be cast yet wider still to include video/webcam responses where perhaps speech or sign is easier than written or graphical communication should resources and time have allowed. Through opening up the channels to include different forms of consent and communicational modes, it may be that more PWLD feel empowered and able to take part in the research process. It is still important to stress that ‘regular’, written forms of research were perfectly suitable for some participants, which gives further credence to the idea of tailoring research methods to best suit the individual.

The questionnaires themselves are integral to the research in three main ways: to provide information for mapping changing patterns of

residency; to provide quantifiable data which can be used to make observations about where PWLD live and why; and to allow participants to self-select for participation in the interview phase. As such, it was important to create a questionnaire which easily allowed for a variety of respondents, with an unknowable variety of learning disabilities, both to understand the premise of the research and to engage with the questionnaire in a meaningful way. One way in which this was achieved is through adherence to the Mencap<sup>12</sup> easy read guidelines (Mencap, 2014) mentioned above. These guidelines outline how information for PWLD can be better designed and illustrated to accommodate for most learning disabilities. It includes advice on the size of font, layout of documents and use of symbols, and has been created by a group of learning disabled volunteers associated with the Mencap group. Using the framework suggested, a plain language information sheet was devised (see Appendix 1) which outlined the research in short paragraphs, under clear headings and included a photograph of the researcher. The questionnaire itself (see Appendix 2) was also devised with this framework in mind. Larger font was used to allow the writing clearly to be seen, and large boxes replaced the standard lines usually seen in questionnaires; allowing sufficient room for non-standard replies, such as larger writing or co-authored answers. The questionnaire also utilised symbols which worked alongside written instructions, showing respondents how to mark the correct box and symbolising thumbs up and thumbs down for 'yes' and 'no'. Given that many respondents filled out their own questionnaire, this perhaps suggests that these endeavours have been useful in engaging PWLD.

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<sup>12</sup> Mencap are a people centred charity who work alongside those with learning disabilities to give them a voice and place within society in a number of ways. Their aim is towards empowering, respecting and including PWLD by transforming lives and challenging discourses surround what PWLD can and should do (Mencap, 2014).

Participants for this phase of the research were recruited through the Learning Disability Database, assembled and held by the aforementioned Learning Disabilities Liaison Team (LDLT) within NHS GG&C. This database holds name, age, gender and address information for over 5000 adults with learning disabilities within GG&C, who have been identified by their GP as having a learning disability. Although potentially not representative of all PWLD within GG&C, it is certainly a valuable resource which makes headway in attempting to recognise and 'get to know' learning disabled communities. Although an undeniably excellent resource, I was, and remain, slightly uncomfortable with the fact that most PWLD with whom I have had contact were unaware that they had been included in such a list or, at least, were not aware that it could be utilised for research purposes. This confusion led to a small number of concerned phone calls throughout the research period which were passed on to the LDLT and dealt with in a sensitive manner. Direct access to the database as a researcher was not available and so, I could only make use of it through the LDLT who utilised their own formal strategy for developing a random sample, of which I was given 2000. It was therefore not possible for me to assess the statistical representativeness of this sample relative to the overall database. An invitation letter, information sheet, questionnaire and freepost return envelope were packaged and sent out in batches of 500 over an eight month period. This gave the LDLT time to sample addresses and create address labels, and allowed for a staggered return in which to process the questionnaires. The return rate is discussed towards the end of Chapter 4.

Returned questionnaires were catalogued using a Microsoft Excel Spreadsheet. Each response was given a number to allow easy identification, and then a note of the answers was recorded. As returns were opened, it became obvious that the questionnaires were

not always answered in a 'standard' format, and therefore it was vital to allow additions and annotations to be noted within the spreadsheet itself, shown in figure 5 below. In this way, the questionnaires have also provided some useful qualitative data, which, although unexpected, should not be overlooked as evidence which potentially reveals a little more about the respondents' lives. When all questionnaires were returned, the spreadsheet easily allowed certain trends in the data to be brought forth for further investigation by filtering for different responses; for example, highlighting those who answered 'yes' to 'have you ever lived in a hospital'. The inevitably simplistic nature of the data revised here is clear but nonetheless draws forth a valuable picture of individualised residential histories and experiences distilled both from the very basic quantifiable data and also the more qualitative scribbled additions on quite a few returns.

1	Questionnaire Number	Age	Gender	Lives with	
66	65	20	F	1	I live with my mum, dad and twin sister
67	66	46	M	5	
68	67	42	M	7	
69	68	57	M	1&2	Mum and 2 brothers
70	69	48	M	6	I stay with my partner who has learning problems
71	70	45	F	1	I live in Goyal hill with my mum and our 2 cats
72	71	68	F	3	I live in a care home for older adults
73	72	33	M		I have 4 staff members who give me 27/7 care. I have supported living accomodation
74	73	80	F	3	I live in Nazereth House, a care home for older adults
75	74	48	F	1	Mum
76	75	68	F		I live with my daughtr and with her kids
77	76	54	M	7	
78	77	48	F	6	My Husband
79	78	29	F	1	Mum
80	79	53	F	3	no
81	80	51	F	3	i live with 2 other persons

**Figure 5.** A small Excel extract of questionnaire responses, cropped to ensure anonymity of personal information.

At the end of each questionnaire, respondents were asked to indicate their wish to take part in the interview phase of the research. Those individuals who so indicated were subsequently contacted, allowing the questionnaire to function as a bridge between different phases of the research; narrowing yet further to begin the more in-depth, face-to-face, qualitative work.

## *Interviews*

At the core of most qualitative research is the one-on-one interview, which itself can take many forms, but this bread-and-butter method presents several problems when considered in the context of learning disabilities. Lewis (2002) suggests that the interview process requires authenticity, validity and reliability in order to ensure that information is correct and representative, but issues arise when verbal communication is difficult. Booth and Booth (1996) found that interviews with PWLD suffered from:

inarticulateness (linked to low self-esteem, isolation and anxiety as well as language skill levels); unresponsiveness in open questioning; difficulty generalising from experience and thinking in abstract terms; and, conceptual difficulty around time, making it difficult for them to tell their story.

As such, Booth and Booth (1996) advise the use of direct questioning without the use of “abstract conceptual or time-orientated questions”; essentially allowing the respondent to develop a mutually trusting relationship with the researcher through treating research as a sharing and listening process, something which could be extended to parents/guardians. Booth and Booth’s (1996) concern over questions which are historical and biographical in nature pose specific problems in this research, since it is deeply concerned with residential biographies and required reflection in a number of ways. By using some of the expressive and creative methodologies, discussed later in this very chapter, in conjunction with ‘standard’ interview techniques, it is still possible for PWLD to be encouraged and enabled to think about, and to respond to questions about their past. Some respondents were only able to do this with help from trusted others, some were able to do it on their own, and others yet still found these questions difficult and could not always answer no matter the method

employed. What has been crucial, as the researcher in this situation, has been to give those respondents who wished to take part, the opportunity to do so, utilising as many methods as need be to allow them to express themselves.

Additionally, Lewis (2004) found that the standard question and answer procedure could be more constraining. Other researchers have used visual stimuli in conjunction with the interview approach, using cards to symbolise key topics in the narrative, such as 'place', 'people' and so on. This use of cards links to systems of Augmented Alternative Communication (AAC), whereby visuals are used to "facilitate not replace" verbal communication by devising strategies for conversation which contribute to a "more relaxed verbal interaction", but problems can arise in the choice of vocabulary (Alant and Bornman, 2012:223). This is where peer informants become useful whereby a person who knows and works regularly with interviewees can help to develop existing vocabulary, so allowing vocabulary to be built expressly upon what they already understand and leaving blank opportunities for interviewees to add their own ideas. Nind (2008) also suggests video recording each session to monitor researched/researcher interactions, as well as eliciting opinions as an on-going process as opposed to an instant answer, although the practical issues involved when interviewing in private spaces of the home would be counter-productive for this particular study.

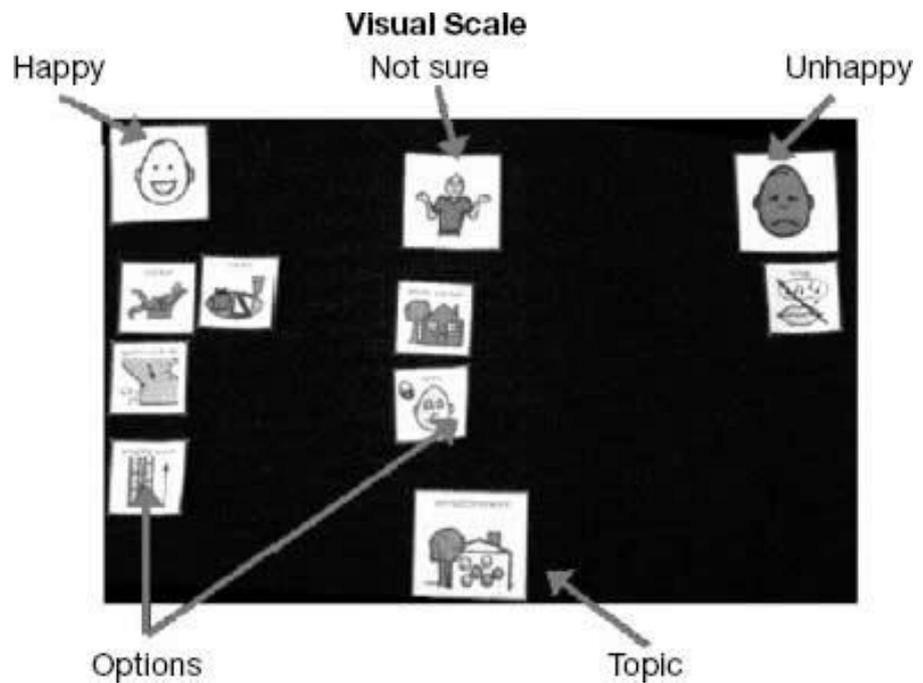


Figure.6. Example Talking mat ([www.jrf.org.uk](http://www.jrf.org.uk)).

Bunning and Steel (2006 in Nind 2008:11) have used Talking Mats as conversational aids within their research, an example of which is shown in figure 6. The above talking mat shows the ease with which respondents are able to place and move symbols around without the pressure of constructing sentences in a short time frame. The visual scale running along the top of the talking mat indicates a scale of emotion from happy to sad under which visual symbols can be placed. These visual symbols relate to the topic being discussed, allowing the respondent to decide how strongly they feel about aspects of the topic. The ease with which symbols can be reshuffled allows participants to consider and re-consider the question asked, perhaps slowly arriving at a decision and recalibrating the speed expected of a 'normal' interview. Furthermore, this form of communication allows researchers to take photographs of the progression of a different kind of conversation:

As well as providing useful reference points during the course of the interview, it [talking mats] gave participants the opportunity to manipulate the content of the discussion. Visual symbols could be selected, newly

generated, altered or moved according to the priority ascribed to the concept by the individual. Each participant was able to check the display on the mat in a way that would not have been possible in an interview that relied on verbal exchange. Importantly, the pictorial representation of meanings allowed for participant verification of the data (Bunning and Steel, 2006:48).

Brewster (2004:168) warns that vocabulary selection is key to avoid “circularity in the process”, through which the researchers only allows discussion on the topics they believe relevant and closing the discussion to anything new or different which might arise in the act of discussion. Cambridge and Forrester-Jones (2003:8) suggest taking into account the individual’s “full communication capabilities, including any residual speech or vocalisations, gestures [and] signs”. Although the idea of ‘residual speech’ comes across as a slightly dismissive term, it serves as a reminder that researchers must be open to the ‘more than verbal’<sup>13</sup> in order to understand as much of the person as possible within the timeframe of the interview setting.

#### *Use of proxies*

For those participants with more profound disabilities, a proxy is often used who speaks on the respondent’s behalf, although Cummins (2002) warns that many proxies find it difficult to separate their own views from those of the respondent, posing ethical dilemmas regarding which voices are being heard. Stancliffe (1999:186) highlights concerns over the use of proxy respondents, with particular attention paid to the disparity in answers given within Quality of Life<sup>14</sup> questionnaires when filled out separately by both respondents with learning disabilities and their carers. Rapley *et al* (1998) found that

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<sup>13</sup> Here we see possibly intriguing links to non-representational geographies which is supposedly always alert to the more-than-verbal.

<sup>14</sup> The Quality of Life Questionnaire measures the relationship between quality of life and other behaviours or afflictions, such as physical health, psychological health, and alcohol or other substance use, allowing inferences to be drawn with regards to areas in need of change.

questions of 'empowerment' displayed the greatest variation, particularly pertinent to the current study, since these questions deal with choice and control in different aspects of everyday life. While the 'reliability' of proxies is questionable, Cummins (1998) suggests that this worry is not applicable to all types of question, further surmising that proxy answers are more consistent on objective issues. Stancliffe (1999:190) is correct to suggest that it is better to have objective views regarding the lives of PWLD than to allow them to remain "disenfranchised" within the research process, but, given the subjective<sup>15</sup> nature of this research about 'home' and 'decision-making', using proxy respondents for those with less severe learning disabilities seems regressive. Clegg (2003) recommends that any proxies used should also be offered the opportunity to give their views on the research separately, perhaps allowing the proxy to put themselves in the shoes of the respondent when answering questions on their behalf and reducing the likelihood of gathering responses which reflect the views of the proxies or their organisations. Alternatively, the presence of significant others (such as parents, siblings, friends, spouses) may provide a response which begins to touch upon those subjective experiences which evolve through close proximity and shared experience. Although imbued with some of the same ethical issues as using proxy respondents, the presence of significant others (who can also be carers) may alone be enough to allow respondents to feel comfortable discussing personal matters, with proxies perhaps able to offer clarity on certain issues, expressions or anecdotes. Considering the complexity of learning disabled lives, combined with the relatively short interview process, this allows the researcher to gain a more rounded understanding of the situations being discussed. In some instances, interviewing significant others regarding their own experiences of living with a PWLD may offer

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<sup>15</sup> 'subjective' in the sense of precisely wanting to find about individual's subjective perceptions and conceptions.

further insight into the negotiations which play out 'behind the scenes', adding yet more texture to narratives on decision-making within and about home-spaces.

As a further bread-and-butter method, it was worthwhile considering focus groups as a potential research tool. Focus groups may have allowed for a more relaxed, less intense research experience than one-on-one interviews, so allowing participants to build confidence in safe environments, among peers. Although certainly not closed to the use of focus groups, this method was not a good fit for these particular respondents, corroborated by Fraser and Fraser (2001:229), who state that focus groups work "for some people with learning disabilities in some situations but not in others". The surrounding literature however, still offered a useful way of thinking about the spaces in which research interactions take place and the impacts that these spaces, and the people within them, can have on the confidence of respondents.

#### Interviewing in this study

Of the 62 respondents who put themselves forward for interview from the questionnaire stage, 32 interviews were carried out with PWLD who represent a variety of age groups and accommodational experiences. An attempt was made to interview each person who offered their time, but there were various reasons why the researcher could not be met or occasions where the respondent had simply changed their mind. Of these 32, eight parents and guardians were also interviewed; four parents on behalf of their relative with learning disabilities, three alongside their relative, and one independent of their relative. It should be made clear that these interviews were not carried out to qualify statements by their relative with learning disabilities, but to give an understanding of the wider impacts of living with a learning disability, as felt by the significant others who are also

entangled within their lives. The interview schedule, shown in Appendix 3 was specifically tailored to meet the outlines provided by Mencap, with questions remaining short, to the point and jargon free. The questions fell under two broad themes which related directly to the overall aims of the research: 'decision-making' and 'home'. Within these themes, sub-themes were devised which teased out further ideas relating to different aspects of policy, environment, networks and connections, family and friends, and choice. Where required, respondents were encouraged to bring photographs or draw pictures of the spaces being explored, annotating the images with memories, feelings and notes about important people. This visual material allowed access to deeper thoughts and ideas, and the use of such visuals will be explored in a moment. Respondents remained relaxed and confident, since the focus remained on what they *could* say and, regarding the visuals, do.

The interviews varied in length, from shorter 30 minute interviews to hour-long conversations. They were mainly conducted over two or three visits, depending on the needs of the respondent, which helped to ensure, where possible, that respondents remained comfortable, both physically and emotionally. If at any point the interview became too tiring or even upsetting, it was immediately terminated and the respondent was offered the opportunity to reschedule at a later date if they wished. Each interview was recorded using either a Dictaphone or an iPhone, and the audio-recordings were later fully transcribed partly by myself and partly by others<sup>16</sup>. Throughout the interview, notes were taken which detailed bodily reactions, uncertainties or any other communicational modes not picked up through recordings. During transcription, these notes were then sewn together with the

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<sup>16</sup> Those transcriptions not carried out by myself were carried out by personal assistants within the administration offices of the Institute of Health and Wellbeing. My concentration lay with those interviews where respondents had the most difficult-to-hear/comprehend communication.

spoken word, carefully documenting and adding corporeal depth to the disembodied interview transcript. The use of the interview schedule to inform the direction of interviews then provided a usual framework from which open-coding could be carried out during the interpretation of the data collected. By drawing out themes in an organic way, the research was open to unexpected anecdotes and unique experiences which, in a rigorously structured study, may not have been discussed.

#### Visual methods in interviews

In conjunction with these aforementioned research methods, use of visual methodologies can also enhance and enrich both the research experience for respondents and the research materials for the researcher. Visual material (pictures, drawings, symbols) can be utilised within research as both a communication tool to aid speech and also as a tool for viewing 'home' (in my research) through the eyes of respondents. Images produced in any form, however, are not without contestation. The technologies which create these images (camera, video camera, computer, hand etc) are not objective viewers playing the 'god trick' (Harraway, 1988), but instead reflect the socially, culturally and politically imbued body which 'captures' the shot. As such, Rose (1996) contests the role of imagery as an objective social 'truth' and instead suggests that images can produce, reproduce and resist unequal social relations in both the creation and the viewing of an image. Entangled in the creation of images is a "personal politics of enacting identity", which highlights visual media as practice and not just representation, thereby binding together points of possible correlation between the use of the visual and the portrayal of thoughts and feelings concerning the home-space (Panelli 2004:152; Crang 1997). Banks (2001:44) argues that everyone, both "observers and observed", constantly 'read' the "internal and external" narratives of the images that we see. As such, he claims that

social researchers need to be attentive to the convergence of the “material, the symbolic, the social and the cultural” in the production and dissemination of images. The researcher should therefore continue to question images, their production and their diffusion through multiple modes of looking.

Dando (2007:17) encourages geographers in particular to accept the “kaleidoscope” of possible constructions of looking, keeping a critical eye open for “patterns that matter”. Elaborating this feminist stance on looking at images, Rose (1996:289) highlights the importance of a ‘certain type’ of gaze which has the ability to inform “powerful social identities”. Borrowing from psychoanalytic thinking, Rose (1996) argues that seeing and being seen are fundamental constituents of social power classification, since “the powerful are those who are culturally constituted as looking [...]”<sup>17</sup> while the less powerful are constituted as those who are looked at”. This stance could therefore undermine the use of images within research as a means of reconfiguring social relations of power, instead handing the power back to the viewer. The researcher/viewer is therefore an important relation of positionality when considering how power relations can be unbalanced by methods such as self-directed photography, in which respondents are encouraged to take pictures of things they wish to showcase, recognising that research situations could be created in which PWLD are both looking and looked at. Rose<sup>18</sup> (1996:290) claims that viewers obtain their position of power when they look upon an image, instantly situating themselves through referent systems of analysis and, as such, geographers and other researchers must be careful not to consider ‘the audience’ passive, having an awareness

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<sup>17</sup> Within this thesis ellipsis within square brackets will denote omitted text, while ellipsis outwith square brackets identifies a pause in respondents speech.

<sup>18</sup> Rose herself, carries out research which unearths the links between photography and home-life, as evidenced by her reflections in *Doing Family Photography: The Domestic, The Public and The Politics of Sentiment* (Rose, 2012).

that interpretation of images may or may not be accurate, or rather are coloured by the researcher who is doing the looking. Ethically, however, the use of images, photographs and/or self-directed photography can allow participants to invite the researcher to share in their home lives in a way which gives them choice over what is viewed and by whom.

Images, particularly photographs or drawings, need not be merely an illustrative addition which breaks up text, but rather can function as a starting-point from which text can be produced by both the respondent, in telling stories about the images, and the researcher, in interpreting the image. Furthermore, images can allow the researcher to 'dig around', allowing them to unearth more about the previously unknown private home-spaces of PWLD. Aldridge (2007) found that open-ended interviews yielded little success with PWLD and so employed visual methods in the form of photographs to allow respondents to choose photographs that they wished to discuss further, or as a method for highlighting something within the photographs better to explain or to expand their point.

Thomson (2000:335) furthers this idea, arguing that the manipulation of power relations becomes an act of individual expression and "artistic engagement", which allows PWLD to "control the terms" under which they disclose information about their home lives. Aldridge (2007) suggests that this tactic focuses more on the capacity of respondents by allowing them to tell of their experiences through photographs. Furthermore, Harris (2003:11) found that the most effective visual resources were respondents' own photographs, taken prior to the research, which showed their families, friends or carers, so allowing them to ground answers in the familiar narratives of their lived experience. Booth and Booth (2003:432), on the other hand, have used photographs to create a 'Photovoice' where the lives of

respondents are explored through the photographs which they choose to take of their lives:

The process challenges the politics of representation by shifting control over the means for documenting lives from the powerful to the powerless [...] Photovoice is all about point-of-viewness: it sets out to capture and convey the point of view of the person behind the camera. Photovoice invites us to look at the world through the same lens as the photographer and to share the story that the picture evokes for the person who has clicked the shutter.

It can clearly be seen that this method is highly subjective and effectively overcomes verbal or written communication problems. Within my particular research, it was a good starting-point for discussing 'home' in an interview setting, perhaps comparing old and new images of 'home' and building talking mats, themselves visual, around these images rather than around symbols. The sharing of photographs, and the familiar narratives which they depict, allowed participants the opportunity to relax, alleviating the pressure of saying the 'right' or 'wrong' thing. For the purposes of this research, three participants were provided with a disposable camera and asked to create pictures of their own homes and spaces of meaning, as opposed to using old family pictures, in order that their own focus was expressed.

#### *Life-course case-studies*

Narrowing the research further still, life-course or narrative research is a method which again lends itself well to collecting data which empowers participants by allowing them to share their life-stories in their own words. Atkinson (2004) has successfully used this approach, arguing that it can empower PWLD through a further understanding and knowledge of their worlds and their place within it. Because the stories told are personal, PWLD are able to tell them in their own way and through their own method of communication, creating a more

relaxed 'storytelling' atmosphere which puts the respondent in control, allowing them, if they wish, to invite friends/carers/family to be included within, and to add to, their story. Nind (2008:14) argues that these narratives cannot be depersonalised, and so enables participants to "emerge as people not cases, to reclaim their lives as their own and to provide counter narratives" to that which may be believed about their lives. Ethically, researchers must be aware of the impact of such narratives as people perhaps recount upsetting stories or come to new conclusions about their lives. As Nind (2008:14) reminds, this method also requires that researchers commit themselves to detailed listening, taking on board the pauses, the silences, the rewordings, the physical bodily reaction to the story and the changes that this attentiveness will require during the transcription of such work. As such, it requires time and perhaps several ways of documenting the experience to allow the whole picture to be taken into account. Like other pieces on 'life histories', such as Atkinson and Williams (1990) and Booth and Booth (1994), Goodley (1996:334) argues that these writings "remind us of the lives that exist behind a label". Through life histories, researchers can therefore pay attention to 'insider' perspectives; as Thompson (1988:265) put it; "[life histories] gives history back to people in their own words. And in giving them a past, it also helps them towards a future".

Plummer (1983) takes a more radical view on the potential strengths of life histories, suggesting that other, supposedly 'objective' methods allow only for a surface description of social phenomena and therefore fail to provide any understanding of narratives within their wider social contexts. Furthermore, Stott (1973) suggests that objective methods allow the reader to understand stories intellectually, but may not allow for an emotional, human comprehension. Goodley (1996:335) believes that "empathy

accompanies insight – we know another’s life because we feel it”, and can therefore be used a research method in itself. Essentially, he argues that reading deeply personal accounts allows the reader to challenge their own ‘truths’, becoming more involved in the narrative and recognising within the story wider structures and environments which could impact upon the story teller. Moreover, by tackling the story emotionally, the narrator’s own words “force us to think of subjects as people, and categories of all kinds become less relevant” (Bogdan and Taylor 1976:52). Through a promotion of “empathy, emotion and feeling”, life histories could help people with different labels to look instead at their similarities by opening up the “social worlds that they inhabit” (Goodley 1996:336).

Building more on the narrative as a research method, life histories can also become a medium through which more in-depth interactions can be explored, uncovering yet more about the connections between social and individual worlds. With its roots in symbolic interactionist paradigms (see Blumer, 1969; Ley, 1979), this form of social research aims to explore the reflexivity of the human experience, bringing to the fore those changing material and social networks negotiated throughout the life-course; changes which could be difficult to address with learning disabled participants through direct questioning (Caswell and Symon, 2004:34). Attempting to combine the social with the individual in this way has not been without contestation; many studies have been criticised for being ‘over-theoretical’ and jargon-heavy, deviating too far away from the original source rather than finding a middle ground between the two. Schutz (1964), in particular, has expressed radical views on this matter, suggesting that theories “flounder” when they are not properly immersed and anchored in the worlds of those that they are trying to understand.

Life histories have been nonetheless welcomed as a more “insightful method of representing the individual (our storytellers) and society”

(Goodley 1996:336). Oral histories and story-telling are recognised within geography as expressive forms of academic research and writing (see Lorimer, 2003; McDowell, 2003; Riley and Harvey, 2007; Parr and Stevenson, 2013), Lorimer and Parr (2014:543) propose that “[story] telling ought never be thought of as an easy option or innocent act” and as such can be politically and culturally enlightening and empowering. For Bertaux (1981 in Goodley 1996:337), the telling of life stories brings to the surface “underlying socio-cultural relationships” which allows a connection to the “broader structural horizons” which could be said to permeate private lives. Furthermore, Goodley (1996:337) suggests that personal stories remind the reader of the “fluidity of individual experience”, which can be lost in purely theoretical accounts, and challenges dominant discourse about the homogeneous nature of a group labelled ‘learning disabled’. Through recognition of the “variability of experience”, researchers are able to take steps towards empowering those with whom they research (Goodley, 1996:337). As far as possible, the researcher should be attuned to the views of the storyteller, since, as previously observed, informants may rank the researcher among other professionals who drift in and out of their lives. Goodley (1996:339) therefore recommends being acutely aware of “our own feelings, perceptions and speech”, arguing that this will make researchers more able to hear the stories being told:

To acknowledge the pen of the researcher in the writing of life histories does not detract from the potency of the narrative, rather it excavates many issues of power that are often submerged amongst the rhetoric of ‘empowerment’ (Goodley, 1996:340).

Writing ‘stories’ can be added to through visual methodologies or conducted in groups to add new dimensions to the stories told, allowing researchers to see the same situation from a number of different angles.

Working alongside PWLD, Walmsley (1995) developed visual life histories and network 'maps'<sup>19</sup> (shown in figure.7 and figure.8 below), combining illustration with narratives to create a research timeline. Adding a visual element allows verification of the data and further encourages and develops thoughts, feelings and emotions as attached to time and place; a concept which can be difficult to address for some PWLD. This method of data collection may also utilise photographs and anecdotes to enrich it, perhaps suggesting other topics for discussion at a later date.

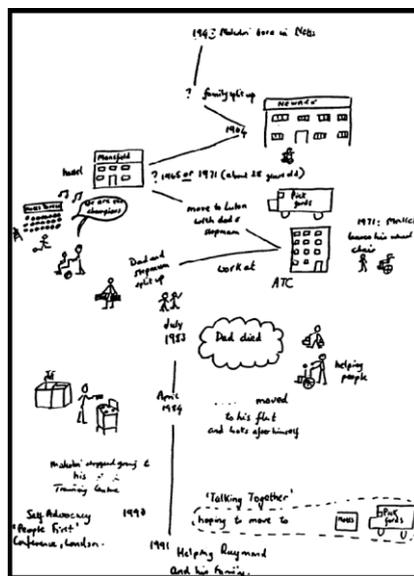


Figure. 7. Showing life map (Walmsley 1995:74)

<sup>19</sup> Life maps are created along a time-line and punctuated by life events which are picked out as important by the respondent. Network maps are a visual detailing of the actors and places involved in, for example, daily interactions in the community. My own work sought to document residential time lines while also thinking about the networks and experiences afforded by the home as the central focus.

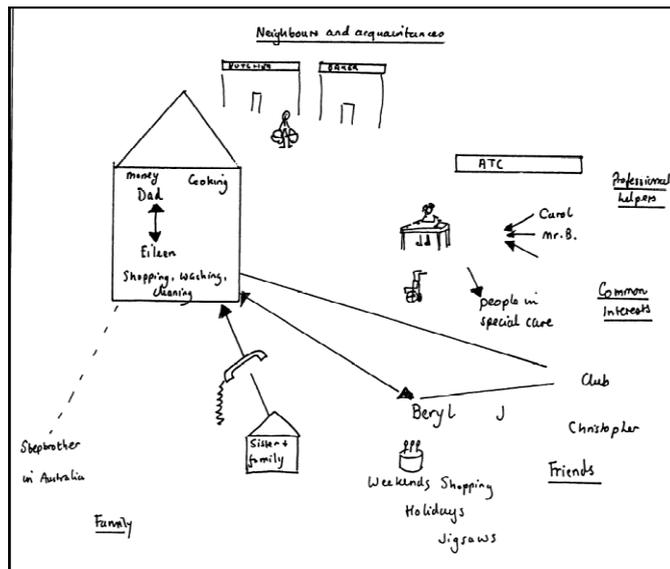


Figure 8. Showing network maps (Walmsley 1995:75)

Some weaknesses have, however, been associated with using life histories in research. Using this method, the creativity of the researcher is called into question, requiring that the researcher should be able to form 'artful stories' (Plummer 1983), but this fails to reflect the ways in which life histories might be beneficial for those who have different communication skills, such as PWLD. Furthermore, Goodley (1996:342) argues that failure to "consider the importance of inarticulate people renders much life history research fragile". Though stories are deeply personal in nature, researchers must be careful not to overlook the social aspects which might be evident behind the story, even if not expressly stated. The development of personal relationships between the researcher and the PWLD is a thin line to walk, since closeness may elicit better, more in-depth stories, but being too close may lead to misrepresentation or, rather, overrepresentation of the researcher within the story. Goodley (1996) argues that a failure to locate stories within their social contexts and theories jeopardises not only the research, but, more critically, the world of the informants which may lead to isolating theories of disability which fail to take disabling environments on board. This is particularly relevant for the geographical researcher in the field of

learning disability since issues of location and context precisely must *not* be obscured, rather explicitly foregrounded.

Plummer (1983) is critical about the use of such methods, suggesting that informants may rehearse stories or lie about certain aspects, perhaps inscribing events with meaning after the event. I would argue, however, that this possibility of 'deception' arises with any method of data collection from live, socially and culturally interacting subjects, and there appears to be no reason why those with learning disabilities are more or less likely to embellish than are any other respondents. This view seems to reflect a lingering sense that a labelled mental 'deficiency' renders the testimony of PWLD somehow less reliable, whereas, arguably, lying constitutes a highly developed cognitive skill that many PWLD may not possess; their testimony might hence be more likely to tell truths. In involving PWLD, the issue of 'bias' can become more complex since, the researcher may also have to interpret what is meant rather than writing it word for word. In this way the researcher runs the risk of adding in more of their own "assumptions, understanding and ambitions", leading to a questioning of who exactly is being represented through the research process (Goodley, 1996: 340). Moreover, Goodley (1996) suggests that we cannot separate the tale from the telling, and so researcher motivations may be reflected in the final version of the narrative. It is therefore the role of the researcher to be aware of the impact that they can have on the stories being told.

#### Life-course work in this study

The case-study phase of the present research was designed to delve yet deeper into the personal experiences of a group of five adults with learning disabilities. In actuality only two case-studies and two separate photo-diaries were completed due to time-constraints and illness of participants. Combining both visual and narrative forms of

research, these case-studies have sought to explore in-depth personal interactions in the spaces and places where respondents live their lives. Participants for this phase were recruited through Inform Theatre Company, a Dundee-based theatre group who aim to highlight and give voice to learning disabled life experiences. I first made contact with this group at an ERSC funded seminar series titled 'Rethinking Learning Disability'<sup>20</sup>, where Inform performed short sketches which formed the basis for group discussions on matters such as 'home' and 'policy'. Having built connections with a number of the group members over the course of the three seminars, it became clear that Inform would be willing to take part in further research concerning PWLD.

Over a five month period, I attended Inform's weekly drama meeting at the Dundee Repertory theatre, participating as a group member and so allowing me to get to know individuals and to build trust. In line with the ethos of the group, I was asked in my first week to be open about my research and also my role within the group as a researcher. Information sheets were handed out and group members were asked to come forward if they wished to take part. It was important, both to me and the group leaders (a group comprised of facilitators, volunteers and occupational therapists), that 'choice' remained firmly in the hands of the company members and that nobody felt forced into participation. In one-on-one interviews lasting between 30 minutes and one hour, the life-course case study participants and I created life-course accommodational time-lines and network maps, using drawings and photographs in a 'talking mats' fashion as a basis for discussion. Framing conversations around the broad themes of 'decision-making' and 'home', respondents' current living arrangements became the starting point from which surrounding neighbourhoods could be explored. It became a fixed

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<sup>20</sup> [www.rethinkinglearningdisability.net](http://www.rethinkinglearningdisability.net)

space from which we could navigate to the other places of importance which impact on their lives. These methods also drew forth spatial observations, whereby, for instance, the park is shown to be actually to the right of the house but further away than the Spar. This method encompassed the interactive nature of lives, building connections which could be difficult to navigate using words alone. As with the interview phase, these conversations were recorded and transcribed, and so, interpreted through open-coding. Moreover, this method also offered up images for critical analysis, so serving as data themselves as opposed merely to qualifying the written or spoken word.

### ***Reflection on ethics***

Given earlier discussions regarding the treatment of PWLD within research, it is understandable that projects such as this are subject to rigorous ethical approval. This particular study required a two-pronged process of ethical approval which was passed through NHS Ethics Review and University of Glasgow, Medical, Veterinary and Life Sciences (MVLS) College Ethics Review. As the data set from which I would be sampling for the mapping, questionnaire and interview phase of the research was held by a team within the NHS, the research required clearance through the NHS Multi-Centre Research Ethics Committee (MREC). This process involved working through an online Integrated Research Approval System (IRAS) form, which broke the research into various categories to allow a detailed and comprehensive review to be undertaken. Alongside the online form, the process also required a protocol, cover letter and drafts of all invitations, information sheets, questionnaires and interview transcripts to be reviewed by the MREC ethics panel alongside the online form.

The process of completing these forms to a high standard proved to be extremely time consuming. I found walking the line between my

expectations for the research and the reality of what could be ethically approved a highly frustrating experience, which relies heavily on the understanding of the ethics panel in charge for proposed research to be validated and, ultimately, passed as 'safe' when working with vulnerable groups such as those with learning disabilities; a problematic also acknowledged by Walmsley and Johnson (2003). Despite the fourteen years which have passed since the Walmsley and Johnson article was written, my experience of navigating these tensions has been somewhat similar when attempting to undertake social science/humanities research within a clinical setting. Goodley and Moore (2000:887) claim that the distinctions within academia between theory and practice continue to push the academic world and the world of the "real, lived experience" further apart. I witnessed this gulf personally when I was asked to attend an NHS ethics panel. There was unease about my inability to describe exactly which methods I would use with which individuals, which was not my attempt to be obtuse; instead, I wanted the panel to understand the suite of methods from which I could pick, should they be suitable for the individual in question. Although ethical consent was eventually given, this was not without my having to cede some of my ideals. I had wanted to craft a questionnaire which could be co-edited with a group of learning disabled individuals to add to the co-produced nature of the research, and to ensure that it was, as far as possible, accessible for those who would be using it; but the existing ethical protocol made such *prior* contact impossible. I found this level of conformity difficult to navigate without feeling like I was being asked to give away little bits of my ethos for the research. It simply had to fit inside 'the box'. It had never occurred to me that the methods of inquiry which I planned to utilise were so very different from those now familiar in clinical science so as to cause such concern. To my mind I was, to misquote Wolpert (1980), allowing participants the 'dignity of difference' as opposed to insisting upon consistent research methods

based on “conventional principles” (Aldridge, 2007:5). After attending to a number of changes and additions, the study was resubmitted and passed by the MREC ethics panel, allowing it then to be submitted for approval by the local Research and Development (R&D) office for NHS GG&C. Again, this required several changes and adjustments which required the resubmission of paperwork from the MREC, holding the research back further. The final stage of clearance required an NHS ‘passport’, which entitles the holder to three years of access to specific sites within the NHS, in my case the database at GG&C. This process entailed further forms on occupational health and a new Disclosure Scotland certificate before the passport could be issued. This level of bureaucracy slowed the PhD process almost to a halt, barring any face-to-face research from taking place for a considerable time.

It is clear that medical models, such as random control trials, still rule the roost within clinical settings, potentially militating against the production of social science research which looks to utilise more co-productive, qualitative methods. It is therefore important to recognise the barriers which still remain to this form of research, especially within the clinical setting through which I have been moving. Potentially, then, these barriers impact not only on who can carry out research, since the time-frames are not catered for within a three year PhD, but also on who can take part in research and how. It would seem that a middle ground needs to be reached, one which faces the often unthinking protectionism surrounding those with learning disabilities and in which PWLD can be safely accessed through NHS clinical settings, which is in point why I have explored the origins of such protectionism – and its possible critique – at some length earlier in this chapter. More importantly, those reached must have access to creative, different, participatory research within a NHS context in order that their voices truly are heard.

Given the time-constraints presented by the clinical route of ethical clearance, the decision was also taken to pass a smaller side project through MVLS College ethics, which could run parallel to the main body of research. It was decided that the life-course case-study phase of the research would be best suited to this component, utilising connections already established with Inform Theatre Company in Dundee to create a small pocket of qualitative, narrative and visual based inquiry, which gives texture to the main aims of the overall project. This work straightforwardly passed through MVLS ethics, so allowing the research phase of the PhD to begin, despite hold ups in other areas.

### ***Collection and processing***

Having gained ethical clearance and carried out the research, the next phase of the study began in the processing and analysing of gathered quantitative and qualitative data. Using Microsoft Excel to gather and order the questionnaire returns allowed the answers to each question to be filtered, creating numerical data which could then be compared, contrasted or tabulated to show general trends in the sample; for example, the number of adults with learning disabilities who have lived in a care home. The qualitative annotations also included in this newly created Microsoft Excel sample database were analysed and included in the same manner as the interview transcripts, life-histories and network maps, to be detailed below.

In the analysis of the interview transcript data, life-histories and network maps, I made the deliberate choice to avoid the use of software packages like Nvivo. Instead, I opted for a purposeful, tactile immersion in the material which kept the human, subjective experience at the fore. Before beginning coding I first spent time re-reading transcripts as if one large volume, without drawing inference or pulling out themes; simply familiarising myself with the experiences

of respondents. In the same open-minded way that I approached the research phase, so too did I approach the analysis; aiming to allow the voice of the respondents to lead the findings by the use of coding (Strauss and Corbin, 1990).

Three initial themes made themselves apparent; 'decision-making', 'movement' and 'belonging'. These themes were identified within the transcripts using colour coding and from these, sub-codes and sub-sub-codes were then devised, many of which could be found under each of the three main themes. When these multilevel codes had been solidified, so began the process of creating coherent chapters, and a little of this process is shown in figure 9 below. All themes and codes were presented on card, allowing them to be moved, promoted and demoted as I worked through the shape of each chapter and devised links, similarities and differences. Analysing in this way allowed a non-linear exploration of the data which stitched together subjective life-stories into one, unfolding narrative.



Figure 9. Showing part of the process from data to thesis.

As can be seen throughout this chapter, there are many ethical and practical considerations which have to be taken into account in order to research successfully with PWLD. Ethically, it is important to be

aware of how researcher/participant relationships may affect participants during and after the research process, requiring the creation of alternative conversations which fully explain research in the most appropriate format for individual needs. Moreover, the inclusion of all PWLD in research about their lives, slowly chips away at the homogeneous label, recognising the diversity within learning disability. When considering consent, it is important to recognise the ways in which the researcher can re-produce information which would allow PWLD to give informed consent, if not for themselves, then by communication through a proxy. Importantly, these seemingly alternative methods for consent should not preclude participation in research, but rather bring light to the need for updated, open and empathetic approaches to research in clinical settings with learning disabled participants. The methods for data collection, described above, aimed to take into account the multitude of different learning disabilities which could be encountered 'in the field' by accounting for differing forms of communication which could best allow and empower PWLD to take part in research which discusses their lives.

## Chapter 4

### Mapping Residencies:

#### **Where people with learning disabilities have lived and do live**

This chapter turns away from understanding the growth of learning disability as an area of academic interest and, instead, aims to uncover the historical spatial practices of policy-making which first sought effectively to remove unproductive bodies from the corpus of society, both physically and conceptually. Moreover, it tackles the resulting and ongoing social and political thinking regarding the 'where' of learning disabled residency by delving into those discourses which have shaped the residential histories of those whose voice is later heard within the thesis. Additionally, the contemporary outcomes of such discourses, and the first empirical materials for this thesis, start to 'map' the present-day residencies of PWLD in the principle study area of this thesis, Greater Glasgow and Clyde.

It is important to consider how place has been embroiled within the story of residential histories of those with learning disabilities. As evidenced in Chapter 2, place is considered a geographically important concept, since, as Tuan (1977) posits, place is the site at which meaning occurs at a range of scales. Considering space within the study of learning disability research has the potential to open up knowledge of the important, often subjective, interweaving of social, political and economic experiences which combine to add to the corpus of work on how learning disabled lives can come to be known. This offers a better and fuller understanding of how 'places for PWLD' are carved out within a society, both historically and contemporarily, constructed as they are around those considered able-bodied and able-minded. Macintyre *et al's* (2002:125) study into "place effects"

adds weight to Andrews *et al's* (2012:1) assertion that place matters to health, suggesting that “where one lives, works, socialises and how one uses the environment has profound health implications”. It is therefore essential when thinking about the everyday complexities of the residential experience of PWLD, and also to consider their relationships, both in the past and currently, with those spaces and places encountered at home and within the community.

With this said, it is key to begin by understanding how the institutionalisation of PWLD first became normalised practice, moving on to highlight the processes of deinstitutionalisation<sup>21</sup> which have resulted in the variety of residential landscapes witnessed throughout this research. Specifically relating to the Scottish context of residential decision-making, movement and belonging, there are two particular policies to which this chapter turns in order better to frame the lived realities of the stories told later by respondents. By critically approaching both *The Same as You?* and *The Keys to Life*, successive Scottish policy statements about the treatment of PWLD, a picture of the residential landscape, both real and envisaged, begins to become apparent. By then mapping parts of these new residential landscapes, we begin to see what deinstitutionalisation actually looks like on the ground, and, furthermore, how those with learning disabilities can become a mappable, knowable population. In seeing these residential patterns, questions begin to emerge about the down-scaled realities of these home-spaces, their communities and the involvement of PWLD within these spaces and places.

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<sup>21</sup> The terms ‘institutionalisation’ and ‘deinstitutionalisation’ imply two entirely separate and distinct landscapes of care and residence. These terms do not highlight the complexities and multiple experiences of those PWLD who lived in and/or were moved from these institutions, nor the uneven timescales over which these changes took place and the current reality of ‘community care’. It is in acknowledgement of these terminological shortcomings that I use these phrases more as indicative of changes in political and cultural discourses surrounding residential landscapes for PWLD than to denote any concrete geographical location or homogeneity of experience.

### ***Social change: from institutions to deinstitutionalisation***

In a time of de-institutionalisation (can we yet claim post-institutionalisation?) it is not merely a matter of drawing a line under institutionalisation as a set of archaic practices. Rather, it must be acknowledged that these residential spaces for PWLD are not “unchanging monoliths”, but “cultural artefacts” which part-represent the changing ideologies which surround learning disabilities (Radford and Tipper, 1988:4). It must be acknowledged that the political and cultural processes which led to the seclusion of those with learning disabilities in the past cannot just be erased or ignored, but rather recognised as ones ever changing and morphing to fit new and emerging discourses regarding what it means to be a learning disabled person. To ignore the deeper histories is worryingly to suggest that we, in the here and now, have reached the pinnacle of learning disability knowledge and, therefore perhaps, equality. I would argue that this is not the case, nor is it a helpful standpoint from which to begin an investigation of residential spaces for those with learning disabilities. What is of interest here is how ‘the institution’ – the institutional response to learning disability – came to be, how these spaces changed in their approach, and how the institutional discourses forged then brought about de-institutionalisation, impacting on the decision-making, movement and sense of belonging experienced now by those with learning disabilities.

‘The institution’ itself has been widely addressed by various academic communities, but somewhat less attention has been given to understanding the roots of the learning disability label before the ‘infamy’ of the ‘idiot’ in the late-1800s. Goodley (2013) discusses the ‘creation’ of the so-called idiot category in the British context, arguing that it is possible that learning disability as a form of human being-in-the-world did not exist before that time; but rather, echoing the thoughts of Philo (1987), proposing that the urban-industrial

processes of the nineteenth century rendered these individuals more apparent. Particularly in an urban context, close living and working brought to the fore the 'idiot' as a visible and unsettling influence upon daily lives, one impelling the state to intervene. Jenkins (1998:17) argues that this conspicuousness grew hand-in-hand with the development and dominance of a statistical measure of normalcy, which simultaneously defined the 'typical' way in which humans 'ought' to be, while marking out those who were 'below average' and, as a result, potentially dangerous to the health and wellbeing of the general population. Creating this 'model of normal' lent seeming scientific legitimacy to criteria of adequacy, consequently generating an objective model at the time "beyond any doubt or reproach" (Jenkins 1998:18). These scientific tropes framed a demand for specialised institutional care that would spatially separate those who *could* from those who *could not* think and behave 'properly'. This construction, Goodey (2003) argues, resonated both politically and culturally with a growing international concern regarding national efficiency in an industrialising and competitive society (Thomson, 2010:119). It is important for Goodey (2003) that learning disability be read through a historically contextualised lens, where worth of the individual was more concerned with the productive, efficient use of time, rather than any personal achievements held within it. As Philo (1987) suggests, industrial capitalism worked to generate and reinforce those who could and could not usefully participate in the industrial advancement of the general population, mirroring Oliver's (1990:34) assertion that disability is produced in the complex entanglements of the "modes on production" and the "central values of the society concerned. Arguably, these themes still resonate to date, both within the disability literature and for those with learning disabilities who wish to enter the labour market.

### *Economic activity and the disabled body*

This focus on the economic productivity of the individual shifted attention to the poor and, with the Poor Law Amendment 1834 and its Scottish equivalent in 1845, there began a growth of workhouses and poorhouses across mainland Britain<sup>22</sup>, in which the 'less fortunate' would be compelled to work to earn their keep. However, the "long-term population of the chronically sick, incapable and aging" within these residential spaces led to a mounting concern regarding the links between the problem of 'mental disability' and wider 'degenerate' populations (Bashford and Phillips, 2010:117). Anxiety was heightened by a growing belief in the hereditary nature of so-called 'feeble-mindedness', making 'madness' and 'mental deficiency' an alleged difficult-to-contain blight on the population, leading to overall cultural disintegration and hence a call for separate spaces where 'lunatics' and 'idiots', respectively, those with mental health problems and those with learning disabilities, could be removed from the public realm to receive appropriate care (Philo, 1987). These fears took form in the shape of 'the lunatic asylum', providing a Britain-wide but patchwork, provision of care which now created a geographical residential location for the lunatics and idiots away from centres of population and industrial productivity.

Foucault (1967) and other historians of psychiatry describe the emergence of 'lunacy' as the creation of a distinct socio-medical object, and it might be argued that 'idiocy' emerged from the set-apart specialist space of the lunatic asylum as a source of previously (largely) unidentified concern. With a growing distinction between 'lunatics' and 'idiots', residential places and spaces for idiots were removed not only from the workhouse but also the lunatic asylum,

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<sup>22</sup> The workhouse landscape was not uniform across mainland Britain and many more workhouses appeared in England and Wales than in Scotland. New poorhouses, as they were called, were rarer in Scotland because more emphasis was placed on the merits of outdoor relief (Young, 1994).

creating new and distinct residential locations for those we would now term learning disabled (Philo, 1987:16). Regarded as a creation of Victorian philanthropic thinking, the idiot asylum (or colony) aimed firstly to train 'idiots' through administration of 'moral treatment', reflecting very deeply grounded beliefs surrounding honest labour and fresh air (Radford and Tipper, 1988; Radford and Carter Park, 1993). Much like Radford and Carter Park's (1993) example of the Orillia Asylum in Toronto, the British picture of idiot asylums found them geographically located on the outskirts of larger towns and cities; close enough for 'patients' to be swiftly removed, but far enough away from the city for them to pose a significantly reduced threat to the increasingly sanitised Victorian population. The 'where' of learning disability then has hence been, since the Victorian Era, of utmost importance socially and politically.

In England, the County Asylum Act of 1808, laid the legislative groundwork for the first generation of specific county lunatic asylums; these did not become mandatory until 1845, but there already stood a network of voluntary lunatic hospitals which foregrounded their appearance<sup>23</sup> (Smith, 1999). The completion of both Bedford and Nottingham asylums in 1812 signalled the beginning of a collective national system of county asylums in England and Wales, with central control over the care provided (Smith, 1999). Unlike England, Scotland sought a more obviously "mixed economy of welfare" (Houston, 2014:304), initially with only limited impetus towards specialist institutions, and the public control of lunacy provision was not actioned until the General Board of Commissioners in Lunacy for Scotland was established in 1857 over concern that care was not being adequately regulated and controlled (Anderson and Langa, 1997). Predating the creation of the General Board of Commissioners, the

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<sup>23</sup> Such as Bethlem Hospital (as early as the 1300s), Bethel Hospital (1713), Manchester Lunatic Hospital (1770) and York Asylum, to name but a few (Parry-Jones, 1972)

development of lunatic-specific Scottish asylums began to emerge almost a decade later than in England, with the establishment of district asylums, said to differ from their English counterparts in their “kind and libertarian” approach to care in which restraint was not expressly a main feature (Anderson and Langa, 1997:248). By 1913 there were seven royal asylums, 21 district asylums<sup>24</sup>, one parochial asylum<sup>25</sup>, three private madhouses and 14 poorhouses licenced to receive lunatics. Moreover, the “boarding out” of lunatics to the domestic care of guardians (Sturdy, 1996) was practised in Scotland, Young (1994) adding that the provision of care was so forward-thinking that even the Scottish poorhouse was incomparable to the English workhouse, since in Scotland more weight was indeed placed on “‘outdoor’ support in community settings (Philo and Andrews, 2014:4); an early attempt at care in the community. Displaying a vast array of approaches to care for people deemed mentally unfit, the Scottish landscape of care was hence unique in both form and practice to that of England (and Wales), and Ireland.

During the late nineteenth century the Scottish landscape of care saw the rise of the philanthropic idiot asylum, far from the public, state-run lunatic asylums. Scotland’s first institution for ‘imbecile children’ was opened in 1855 by Sir John and Lady Jane Ogilvie who themselves had an ‘imbecilic’ child (Egan, 2001). Based on Dr Johann Jakob Guggenbuhls colony model (Henderson, 1964), the Ogilvies opened villa accommodation in their Baldoran estate near Dundee (pictured below in figure 10). The Ogilvies efforts were matched by those of Dr and Mrs Brodie who were central in the foundation of *The Scottish*

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<sup>24</sup> These asylums were established to provide pauper patients with services in areas not already provided for, included those in Lochgilphead, Argyll (1863), Perth (1864), and Inverness (1864), to name but a few.

<sup>25</sup> Parochial asylums were those erected from the taxes levied at the parish level and, in 1860, included those at Barony, City of Glasgow, Govan, Abbey, Paisley Burgh and Greenock. The popularity of these asylums fell as they were incorporated by district asylums and, eventually, NHS hospitals (Sturdy, 1996).

*National Institution for the Education of Imbecile Children*; later The Royal Scottish National Institution for Mental Defectives (Henderson, 1964; Egan, 2001). Together with Dr John Coldstream, The Brodies established *The Society for the Education of Imbecile Youth in Scotland* in order to raise money for the creation of a national institution for Scottish Imbeciles; eventually realised in 1863 with the opening of an institution in Larbert, Stirlingshire (Egan, 2001). The rise of such institutions added to the patchwork of public, charitable, and private care available for the 'idiot'.



**Figure. 10.** Baldovan Institute, Dundee ([www.leisureandculturedundee.com/localhistory/exhibitions](http://www.leisureandculturedundee.com/localhistory/exhibitions))

Towards the end of the nineteenth century, Thomson (2010:117) suggests that a new concern for the health of the general population caused a shift in the discourses surrounding both 'lunacy' and 'idiocy', resulting in a turn away from the philanthropic practices of the nineteenth century such as that described above (as much as it can be suggested that those with learning disabilities did fall under this philanthropic gaze to begin with). Radford and Tipper (1988:20) argue that, despite opening under philanthropic, moral justifications, many idiot asylums merely became "dumping grounds for social undesirables", soon coming under the influence of custodial forms of care in which the asylum became a more disciplinary and less

educative environment; much the same claim which can be made about lunatic asylums though these are not the focus of the discussion here. The upshot were uneven geographies of idiocy whereby those institutionalised could be treated in whatever manner deemed fit by those in charge of the asylum spaces.

Throughout this time the idiot body was of course indeed unable to speak for itself, a position of powerlessness mirrored by an increase in eugenic thinking and even compulsory sterilisation programmes throughout much of Europe and North America. In Britain, the implementation of the Mental Deficiency Act (1913) introduced a eugenic flavour to the 'idiocy' landscape, if not through sterilisation then through strict spatial segregation, keeping male and female inmates apart to prevent the 'feeble-minded' from breeding with each other, or with the wider population; Indeed, Radford (1994) discusses asylums and colonies as part of a wider eugenics strategy. Where Trent (1993) maintains that eugenic motives within institutions were belittled in comparison to the need for sterilisation to control populations, maintain order and assert professional dominance of superintendents, Radford (1993) argues that eugenic forces both within and outwith the asylum walls were closely connected to broader social structures. Far from being institutionally distinct from wider social discourse, Radford (1993) situates the eugenic strategies of sterilisation and spatial segregation as reflective of the seemingly pertinent socio-biological issues of the interwar period.

Not until the Mental Health Act (1959) in England and the Mental Health Act (1960) in Scotland did the UK introduce legislation which began to address the physical, mental and social issues raised by institutionalisation, chiefly for people with mental health problems but with implications for people who were now called 'mentally retarded/handicapped' (another forerunning term for learning disabilities). Within this policy, the notion of 'community care' was

taken up, but there was little in the way of funding for such large-scale changes in residency for those with learning disabilities. Changing patterns in residential services for the mentally 'retarded' represented a turning point in thinking about residential spaces and places for those with learning disabilities, aligning itself with the political shift towards new models of community care (Kugel and Wolfensberger, 1969).

### *The decline of 'the institution'*

Mansell and Erickson (1996) suggest the 1970s represented a time of institutional disassemblment in the learning disabilities field, in thought if not always in reality, with the resulting formation and trial of new residential spaces outside of the hospital setting, firstly for those with mild to moderate learning disabilities and then those in need of more specific and specialised care. During this time 'the institution' became the base measure against which the suitability of new residencies should be judged and improved. In 1961 then Health Secretary Enoch Powell, lit the fuse which began the decline of the institution as the only residential possibility for those with learning disabilities, proposing that so-called mental hospitals (the residential asylums of old) should be closed (Open University, 2015). Despite political backing, services were slow to change from the traditional institutional model, as the developments of alternative residential models were trialled. Many institutions attempted redevelopment in an effort to move forward, but it was not until the early-1980s that large-scale residential development began in earnest, the first of which in Scotland saw the closure of Caldwell House Hospital in Renfrewshire (Mansell and Erikson, 1996; SCLD, 2015). These changes were not only actioned for the social benefit of those populations living within hospitalised institutional care, but also reflected fiscal concerns because it was thought that deinstitutionalised systems

would be more economically viable as large-scale institutions became harder to upkeep and more expensive to run.

The first wave of deinstitutionalisation in Britain involved the movement of the least severely learning disabled individuals into community-based hostels, group homes, family placement and independent living situations, so changing the residential landscape from previous centres of care in the asylum to dispersed community-based care (Mansell and Ericsson, 1996). For those with more profound learning disabilities purpose built units were later established with the aim of providing a 'home for life' in which these individuals could appropriately be supported throughout the life-course (Felce, 1989). The pace and nature of deinstitutionalisation varied across the UK, Sturdy (1996) suggesting that Scotland were slower to replace services given the perceived failings of deinstitutionalisation in England and Wales. As such, the percentage decline in institutional spaces for PWLD (and mental illness) between 1980-91 in Scotland was just 24%, compared with 32% in Northern Ireland, 41% in Wales and 51% in England (Mansell and Ericsson, 1996:169).

Throughout the 1980s, PWLD gained small political victories, and in 1982 three residents from Gogarburn Hospital Edinburgh successfully campaigned for the right to vote in General Elections, so pushing forwards rights for PWLD previously unrecognised (Open University, 2015). Further amendments to the Disabled Persons (Services Consultation and Representation) Act 1986 sought improvement in the effectiveness of services and co-ordination of resources for PWLD and mental illness in the UK, outlining the right of the learning disabled individual to be consulted in matters which impact on their lives (UK Government, 2015).

Institutional scandals, such as those later uncovered at Winterbourne View<sup>26</sup> in 2011, cast yet more of a shadow over the appropriateness of the institutional model, even where smaller institutions were involved. As such, many advocacy groups, such as People First in England, called for the immediate closure of such spaces. Within this wider political landscape, Scotland began to shape its own course of action for PWLD living in and then beyond hospital settings. It is these policies to which the chapter now turns, beginning to uncover the most recent changes in how Scottish residency for PWLD has been altered through a policy lens, so changing the landscapes of ‘home’ most familiar to those with learning disabilities today.

***Political thinking: shaping the ‘where’ of Scottish learning disability residency by policy***

Figure 10 begins to give an idea of the Scottish care and residential landscape for learning disabilities from the construction of the first Scottish long-stay idiot asylum for PWLD in 1855 through to early-2005. Of the 36 establishments operational over this 120 year period, not including the early lunatic asylums in which many PWLD may also have found themselves (and detailed in Table 2), 19 long-stay hospitals and institutions remained open at the time of the most influential and significant Scottish policy statement ever to address where PWLD could and should live. The year 2000 brought with it *The Same as You?: A Review of Services for People with Learning Disabilities* (often referred to as SAY?), the first document in over 20 years to question and set action to changes in Scottish residential care for PWLD, pushing forward deinstitutionalisation in a serious way. It

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<sup>26</sup> Winterbourne View was a private hospital for adults with learning disabilities in South Gloucestershire, England, where a BBC Panorama show titled *Undercover Care: The Abuse Uncovered* unearthed large-scale abuse of patients. This footage displayed patients receiving water-based punishment, patients being wrestled to the ground and restrained with undue force, and patients being challenged to so called ‘games of strength’ which they could not possibly win (Flynn, 2012; Flynn and Citronella, 2013; Plomin, 2013).

is this recent policy history which, alongside the *Same as You? (SAY?) Consultation* (2012), *The Keys to Life* (2013) and *The Keys to Life Implementation Framework and Priorities* (2015), continues to have most influence on the residential experiences of PWLD living in Scotland today. This is not to say that these policies are without flaw or a touch of wishful thinking and, indeed, these policies will be critiqued later in this chapter. Nonetheless, these policy documents are pivotal in shaping and moulding the residential landscape as experienced by those whose voices will later be given centre-stage within the thesis.

<u>Institution</u>	<u>Location</u>	<u>Opened</u>	<u>Closed</u>
Armistead's	Tayside	Not known	-
Arrol Park	Ayrshire	Not known	-
Bellefield	Lanarkshire	Not known	1993
Birkwood	Lesmahagow	1923	2002
Bridgefoot House	Tayside	Not known	-
Broadfield Hospital	Renfrewshire	1925	2005
Caldwell House Hospital	Renfrewshire	1929	1985
Children's Home Hospital	Strathblane	1903	1994
Craig Phadrig Hospital	Inverness, Highlands	1969	2000
Dunlop House	Ayrshire	Not known	1991
East Fortune	East lothian	1956	1997
Glen Lomond Hospital	Fife	1948	1987
Gogarburn Hospital	Edinburgh	1924	1999
Hartwood Hospital, Lanark	Lanarkshire	1895	-
Kirklands Hospital, Bothwell	Lanarkshire	1881	-
Ladysbridge Hospital, Banff	Aberdeenshire	1948	2003

Lennox Castle Hospital, Lennoxtown	Glasgow	1929/36	2002
Lynebank Hospital	Fife	1968	
Maud	Grampian	Not known	-
Merchiston	Renfrewshire	1925	2005
Murthly Hospital (originally asylum)	Perth	1964	1995
New Craigs, Inverness	Highlands	c.2000	-
Nithbank	Dumfries and Galloway	Not known	-
Ravenspark	Ayrshire	Not known	-
Royal Scottish National Hospital	Larbert	1863	2003
St. Aiden's	Borders	Not known	-
St. Joseph's Hospital, Rosewell	Midlothian	1924	1999
St. Mary's, Barrhead	Renfrewshire	Not Known	-
St. Mary's Borders	Borders	Not Known	-
Stoneyetts Hospital	Glasgow	1913	Not Known
Strathlea	Ayrshire	Not Known	-
Strathmartine Hospital (formerly Baldovan Institute)	Dundee	1855	2003
Woodlands Hospital, Cults	Aberdeenshire	1948	2003

**Table 2.** Long-stay learning disability hospitals and institutions in Scotland, 1900-2005 (SLCD, 2015)

### *Policy in the Scottish context*

The changes in political thinking with regards to PWLD which lay the groundwork for the publication of SAY? (2000) and TKTL (2013), began in Scotland in the 1980s. Building on cash-for-care-based support schemes evident in the US, England and Wales, Scotland too sought to provide legislation for direct payments which gave PWLD further

control over their care (Arksey and Kemp, 2008). Despite the roll out of the Community Care (Direct Payments) (Scotland) Act in 1996 uptake to the scheme was low and political support limited (Pearson *et al*, 2014). In contrast, Pearson *et al* (2014) argue that the concept of personalisation, as a tool for the reformation of social care, was by the mid-2000s, much more widely accepted and more readily utilised as an underpinning ethos in changing social care legislation in Scotland and the rest of the UK.

### Austerity

These changes to the Scottish policy landscape and the move towards personalisation are framed within the context of UK-wide austerity. Austerity in the UK has been characterised by the government as a “necessary period of efficiency and thrift” in order to recover from the financial crisis of 2009 (Runswick-Cole and Goodley, 2015:145). Jensen (2013) among other commentators, argues that then UK Conservative coalition government merely used the 2009 financial crisis as a way of re-framing a withdrawal of the welfare state in the name of national efficiency. Berlant (2011) offers further critique by suggesting that austerity works simply to mask structural inequality within the UK, instead posing those who claim benefits as workshy. Falling within this category, PWLD find themselves recast as a societal drain (Tylor, 2013) with welfare rebranded as a space for competitive, neoliberal markets to enhance user experience (Runswick-Cole and Goodley, 2015). Within this newly imagined market of care, choice and control over welfare was highlighted as an overwhelming positive of state cut-backs.

### Personalisation

Personalisation encapsulated a number of approaches to social care which emphasised “choice, control and flexibility in social care support” (Pearson *et al*, 2014:15). The publication of *Way Ahead*

(Etherington *et al*, 2009) outlined a further shift in Scottish learning disabled policy, working towards a model for self-directed support and addressing criticism of traditional care management policy approaches, which failed to address the needs of a diverse population (Etherington *et al*, 2009; Fischer, 2009). The Social Care (Self-Directed Support) (Scotland) Act 2013 follows this turn to personalisation, creating a framework for self-directed support which reflects the needs of PWLD in a way which is outcome-focused rather than service-focused (Miller 2012). Self-directed support in Scotland offers support in one of four ways:

1. Direct Payment
2. Support selected by the user but arranged by local authority on their behalf
3. Support organised and arranged by the local authority
4. A combination of numbers 1-3.

These options embrace a wider concept of self-directed support which furthers the involvement of PWLD in the facilitation and management of their care (Pearson *et al*, 2014).

Followed by the Public Bodies (Joint Working)(Scotland) Act 2014 and the Community Empowerment (Scotland) Act 2015, Scottish policy attempts genuinely to “engage people as active participants” by delivering “accessible, responsive services of the highest order and promoting wellbeing” (Etherington *et al*, 2009:2). Ferguson (2012:57) argues that the landscape of personalisation outlined by SDS is merely another contested terrain on which “different social forces seek to impose their preferred reading” without real implication for those whom the legislation should impact most greatly. As opposed to *interdependence*, which understands PWLD as in need of practical support and assistance, Ferguson (2012) argues that personalisation, and the resulting SDS, have created “responsibilisation” (Scourfield,

2007) whereby PWLD are accountable for their own wellbeing, so further shifting responsibility from the state, to the individual.

Within this individualistic incarnation of personalised support dependency is somewhat denigrated, framed instead as unwanted and unneeded state intervention. Furthermore, as repeatedly spoken about within this thesis, denouncing interdependency in this way fails to account for the “mutual dependence” and “vulnerability *all* individuals share” (Hall, 2011:590, italics authors own). A Marqusee (2011) eloquently states, “the struggle for autonomy is one you can’t win on your own”. Coupled with austerity measures and the resulting cut-back of public facilities, Ferguson (2012) disturbs the mirage of choice and control through SDS by pointing out the lack of opportunities for decision-making regarding home of leisure time when services are no longer available. As argued in chapter 5 there can be no autonomous decision-making if there is nothing to choose from.

Ferguson (2012) further highlights the path from “enforced collectivity” to “enforced individualism” as suggested by Roulstone and Morgan (2009). Here, Ferguson (2012) discusses the move from collective LD service provision in day centres, to the closure of such facilities which Hall (2011: 598) terms the changes in the “appropriate locations and relations” of care. While it may be true, as evidenced in Ferguson’s (2012) paper, that day centres services can act as holding places rather as opposed to a place in which PWLD can thrive, so too is it evident from the research contained within this thesis that day centres often provide spaces of comfort and routine. These differing experiences provide “much needed counterweight to the assumptions of the autonomous subject” which prevails in personalisation discourse within policy (Hall, 2011:599).

The simple closure of spaces such as day centres and community centres, then, is antithetical to the claims of personalisation in which a support system would arise which accounted for learning disability as a spectrum in which more or less support would be available dependent on need throughout the life-course; this is clearly not the case. What this points to is a continued mismatch between “transformed spaces and relations of care and their [PWLD] everyday lives, needs and desires” (Hall, 2011:598). Instead, personalisation in the form of SDS works for a restricted number of disabled people, the result, Hall (2011) argues, of a combination of the neo-liberalising welfare state which prioritises the individual and the adoption of the civil-rights based social model of disability by disability organisations, neither of which are representative of PWLD.

This is furthered by Pearson and Watson (2017) who note that austerity measures have increased pressure on existing resources, as such effectively eroding the initial values of independence, choice and control sought by personalised approaches to social care. Ferguson (2012) moves the argument forward further by arguing that these values have been replaced with neoliberal social and economic agendas, evidenced by the reduction in social care spending in Scotland which followed the implementation of SDS in April 2014 (Pearson and Watson, 2017). Crucially, Pearson and Watson’s (2017) research has shown that it is not the legislation itself which is flawed, indeed personalised support packages would be the form of social care to adopt. Rather, it is the implementation of the legislation which has failed to enable the independence, choice and control for PWLD. Despite the promotion of SDS as a coproduced piece of legislation, leadbetter (2004) argues that the development of personalisation as a whole has been somewhat top-down, so failing to instil those everyday realities and experiences which would truly enact positive changes through legislative reform.

Hall and McGarrol (2013) argue that the development of a Scottish-specific learning disabilities policy has, unlike in England and other places, avoided a model of 'commodified care' – where unhealthy bodies become responsible for their own wellbeing in which they become care consumers (Henderson and Peterson, 2002; Hall, 2011). Instead, the policy here has shaped self-directed support based on 'collective provision' of care in which room can be made for PWLD to become "active, informed and articulate participants in their own care and support needs" (Leadbetter, 2004). Hall and McGarrol (2013:160) further suggest that this approach presents a more "positive progressive localism" which recognises place as an active agent, re-imagining how care can be locally negotiated within the dynamic relationships of wider society.

Moreover, the Scottish National Party Scottish Government and the UK Conservative-led Coalition Government (prior to 2014) have held contrasting ideas regarding how social care can be implemented and negotiated in a time of significant reductions in public spending. This form of social policy-making described by Hall and McGarrol (2013:161) has led to the creation of a "different articulation of personalised social care" within Scotland, and not only for those with learning disabilities.

#### *What does policy have to 'SAY'?*

Launched by the Scottish Government in 2000, *SAY?* aimed to provide a review into the services which were then in place to support adults and children with a variety of learning disabilities. The questioning nature of the policy title perhaps gives the first indication of the deeper epistemological and ontological complexities involved in the construction of the policy, which genuinely sought to challenge standard claims around the (in)validity of learning disabled knowledges and also about the subsequent everyday realities of being

learning disabled in Scotland. Just 17 years on, many of the changes suggested by *SAY?* seem mundanely obvious, even questionable in their need to be articulated at all<sup>27</sup>; but, set within the context of a policy landscape which had remained relatively unchanged in the previous 100 or so years, *SAY?* provided a much needed political and conceptual shift in how PWLD were considered within those policies which shaped their lives.

The findings of *SAY?* prompted the Scottish Government – meaning a devolved administration within the UK, given authority over learning disability issues – to suggest 29 recommendations to local authorities which they felt would empower PWLD to find a ‘voice’ and a ‘place’ within society, through contribution in and access to support which should allow them to live a life of their own choosing. These initial 29 recommendations ran across six main themes: understanding current issues; finding ways to forge ahead; building stronger connections between people and policy; understanding where PWLD live; understanding what PWLD do; and integration of services. These recommendations represented a crucial framework which was supposed to, and in most ways did, guide future policy and planning for those with learning disabilities. Reflecting on past institutional constructions of care and support, Grey (2000) suggested that, though well meaning, they lacked in understanding and so *SAY?* attempted to locate and, crucially, to listen to those whose lives were and continue to be entangled within systems of care and support. While *SAY?* tackled a number of issues surrounding health and social care, the attention of this chapter will focus on those recommendations which related to the residential opportunities for PWLD, turning then to reviews and further policy initiatives to understand how their lives

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<sup>27</sup> Such as the suggestion of *SAY?* that those with learning disabilities should have ordinary homes which are private, secure, comfortable and safe.

were impacted as a result of *SAY?*.<sup>28</sup> The significance for the shifting residential geographies of PWLD in Scotland was massive.

Furthering Enoch Powell's initial call in 1961, Recommendation 12 of *SAY?* suggested that by March 2005 all long-stay Scottish hospitals for PWLD should be closed, re-housing those living within these spaces within a community setting, and as such it marked a huge shift in how PWLD were thought about, or should be considered, by professional, health care and local communities. Based on the assertion that people's homes should not lie within hospitalised, institutional settings, *SAY?* (2000:39) suggested that alternative services should be built up within a five-year period to allow appropriate support for PWLD "with their families or in their own homes". Previous attempts to reduce the number of people within long-stay hospitals had already meant a significant rise in the number of PWLD living in nursing or residential care homes, but *SAY?* revealed that local authorities were finding it difficult to arrange such supported living options<sup>29</sup>. A significant number of PWLD who were expected to leave the long-stay environment hence found themselves housed instead in large group or nursing homes, arguably creating new 'asylums' within the community. Although living within less institutionalised spaces – smaller and supposedly more home-like spaces – *SAY?* (2000:38) suggested that "differently institutionalising" PWLD fails to recognise and account for their ability successfully to lead as independent a life as possible when provided with the correct support and care networks.

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<sup>28</sup> The findings are presented in a linear fashion for the purposes of the thesis, but it is recognised that the lives of PWLD are simultaneously impacted by many, if not all, of the issues contained within *SAY?*.

<sup>29</sup> Arguably, some of these options still had an 'institutional' character – not the huge old-style asylums of course, but smaller nonetheless still relatively closed and set-apart spaces.

In dialogue with PWLD, SAY? (2000:39) found that most sought a “choice of bricks and mortar” outside of the long-stay facility, which would empower them to make decisions and facilitate network-building of all kinds within their local communities. It was the aim of SAY?, therefore, to suggest changes at the local level which would pull Scottish learning disability accommodation from its exclusionary shadow, forcing supported housing into the mainstream in its many formats. The closure of long-stay facilities, although seen by SAY? (2000) as beneficial to enhancing the lives of PWLD, did indeed place growing pressures on local authorities and other services appropriately to meet the accommodation and care needs of a growing, non-institutionalised, learning disabled population. As such, SAY? (2000:42) suggested a prioritised gradual shift which would place importance on removing people from long-stay settings over removing people from nursing or care homes, effectively allowing the ‘smaller institutions’ to remain operative. Furthermore, this move would also allow for prioritised funding, and it was argued that the costs incurred by such a radical change in accommodation options for PWLD would be far outweighed by the supposedly positive personal changes experienced by PWLD.

#### *Evaluating SAY?*

The *SAY? Consultation* report (2012:5), which looked at the impact of the original SAY? review and policy framework (2000), found that more than 1000 people had been moved out of long-stay hospitals, counting the closure of these facilities as one of the key achievements of the new policy regime. Moreover, it was noted that more PWLD now experienced supported living than had been the case before the original review, but it was also recognised that many were still housed in inappropriate settings and further highlighted a disparity in the packages of support available from one local authority to the next. Although all long-stay hospitals were intended for closure by 2005 the

*Home at Last?* Report (2004) found that eight remained open in December of that year, providing long-term hospital places for 165 individuals. The *SAY? Consultation* (2012:8) and previous *SAY? Scoping* report (2010) both suggested that this situation resulted from a lack of available housing, compounded by delays in setting up the appropriate care packages within the community which could meet the medical and care demands of individual PWLD. The *SAY? Scoping* report (2010) suggested that, while the majority of PWLD were now living in community settings, the figures (55% since the beginning of *SAY?*) only represented around half of the PWLD within the eSAY database<sup>30</sup> (used to construct and monitor the learning disabled population throughout the report). This number therefore could probably be generally applied to the experience of the overall learning disabled population.

A further facet of the move away from long-stay facilities and looking forward to all care for PWLD taking place in the community, the original *SAY?* review (2000:15) asserted the need to establish independent lives for PWLD, recognising the need for services which could help PWLD to understand information, support them in the decision-making and planning process, teach them new skills in mobility and personal care, and help with communication to and between different services. Furthermore, each of these services should allow PWLD to lead as normal a life as possible best suited to their needs and opinions, be that at home, in work, at school or in any

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<sup>30</sup> The eSay database is the Scottish national learning disability and autism spectrum diagnosis dataset run by the Scottish Consortium for Learning Disabilities (SCLD) and funded by the Scottish Government. It represents all adults with a learning disability and/or autism spectrum diagnosis (including 16 and 17 year olds not in full time education) known to, or in receipt of funding from, the 32 Local Authorities. Given these parameters, it is the case that the database does not count every PWLD living in Scotland, but still remains the most representative and comprehensive database on PWLD in Scotland.

other setting (SAY?, 2000:16), begging questions about what compromises a 'normal' life and against what we measure its success.

In consultation with various service users and their carers/families, the initial SAY? review (2000:22) found that experiences of health boards and community services varied greatly depending on where PWLD lived, a trend that was mirrored in the availability of funding across services and authorities. This move was something that SAY? recommended be addressed in order that PWLD achieve the levels of independent living best suited to their individual situation, and, as such, balancing out an uneven map of service provision.

The establishment of a "network of active support" from family, support staff and local domestic services was seen as essential, using person-centred planning and self-directed support as a means of constructing care and support plans which would supposedly reflect the needs and wishes of PWLD themselves. The SAY? review (2000:41) used public body Inclusion Glasgow<sup>31</sup> as an example of the available package of care available to those leaving the institutional setting. This package included a one-off resource aimed at supporting people into independence as they left the long-stay hospital, as well as a service fund which could be managed according to personal plans and could be spent on care at home, work, leisure or any other pursuits. As the plan moved forward, it was argued, "natural supports and networks" would increasingly replace personal plans, meaning that the fund should reduce or, presumably, PWLD would become comfortably independent (SAY?, 2000:41). This plan could be critiqued as a neo-liberal vision of the 'responsible' citizen who is almost not in need of

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<sup>31</sup> Now simply 'Inclusion', Inclusion Glasgow was established in 1996 to provide supported living for those who had been living in long-stay institutions, particularly Lennox Castle Hospital. Contemporarily, Inclusion provide help and support to aid PWLD in planning and designing care support packages, and help in recruiting and training support staff, creating specifically tailored care packages to support PWLD across Central and West of Scotland to live in their own homes ([www.inclusion-glasgow.org.uk](http://www.inclusion-glasgow.org.uk)).

state 'hand-outs', an extremely tall order both for those who would then bear the financial brunt of having a learning disability or being the relative of someone with learning disabilities, and also those learning disabled individuals who have come to rely on institutionalised forms of emotional and social support.

Moving forward, the Scottish Government prioritised independent living in *Self-Directed Support: A National Strategy for Scotland* (2010) in order to ensure that recommendations put forward by the *SAY?* review (2000) were recognised and adhered to by local authorities. As part of this, the *SAY? Consultation* (2012) evaluated the use of self-directed support, finding that the Scottish Government made it possible for PWLD to organise their own support through options such as direct payment of funds, independent living funds or the option of using different care providers or remaining with local authority support, a complicated entanglement of care needs and service accessibility. On further investigation, however, it appeared that the awareness of schemes such as direct payment was low amongst the learning disabled community, with inequalities appearing across authorities. One change valued by some PWLD and their carers/families was the flexibility in choosing who supported them. Conversely, others who were not benefiting from this scheme felt less able to make decisions or to enact changes, while others simply had no inclination to assert more control over their support, highlighting the crucial variability in wants and experiences across a variety of learning disabilities (*SAY? Consultation*, 2012:28).

Recognition of the need for independence also highlighted the need to recognise individuality, and so the *SAY?* review (2000:43) was keen to promote careful matching of individual needs with the model of care available. What is unclear from the *SAY?* review (2000) is what was then exactly meant by being, and indeed what it could mean to be, independent. Experiences of so called 'independence' with

respect to residencies are further explored by this thesis. The review also saw the need to consider small group<sup>32</sup> housing as a viable (relatively independent) alternative to living alone, and suggested that, although running costs would be higher than for larger home groupings, there might be many advantages. The latter were envisaged to include better access and availability of support staff, as well as a reduction in the need for anti-psychotic medical intervention. Furthermore, the *SAY?* review (2000:43) suggested that small group housing would provide an increase in social interaction, meaning that day-time activities and recreational or community-based activities could be more easily organised and managed. This option would, however, require a careful assessment and planning procedure to ensure that PWLD were always consulted and considered in the home-space, ensuring that those with learning disabilities see the small group setting as the *best* solution and not merely the *only* other option. Clearly, options and choices would need to be well explained and presented to each individual with support staff on hand to help the person live in the community. Upon review, Curtice and Trew (2012:37) find that group accommodation, often acting as a stepping stone from the hospital setting, had succeeded in providing a space where PWLD could be supported with their requirements in a new network of PWLD. For others, the move to a group home was a move away from the familial home-space and the ties it can create, a move which many felt instantly improved their feeling of independence by adapting their support within a new setting. Simply put, one respondent within the *SAY? Consultation* stated, "I had a bad life, but it is better now" (*SAY? Consultation*, 2012:4).

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<sup>32</sup> These small group homes are organised and run by specific housing associations and accommodate between two and four PWLD within family homes. These homes have are fully staffed and key workers are on site 24 hours per day.

Moreover, the *SAY?* review (2000:51) maintained that individual needs and choices of PWLD should be at the forefront of decisions made which impact on their lives, so best representing those with learning disabilities as individuals. It included recognition of the fact that being out of the institutionalised hospital setting does not necessarily mean individuals living completely alone, and could involve any number of cross-overs between group homes, family homes and full-time care packages. Whatever the focus of the support, the *SAY?* review (2000:54) recommended that it should strengthen the ability of PWLD to “make their own contribution ... this may be either to their community, their family or their workplace”. Again, these aims came with certain coded expectations of what ‘proper’ and ‘respectable’ citizens should all want to achieve, suggesting first and foremost that those with learning disabilities are aware that there are decisions and input to be made in the first place. The *SAY? Consultation* (2012:5) found that the majority of PWLD who were approached reported increased feelings of independence, where individual planning and flexible support were available. Where followed up, life plans were also seen to help PWLD achieve hopes and dreams, and to plan the direction of their lives, and in general it was found that a still greater emphasis ought to be placed on support which facilitated independent and healthy lives to that suggested in 2000.

The *SAY?* (2012) found that younger people were more likely to be living at home with their families, with those PWLD over 35 tending to live more independently. It is nonetheless questionable how closely having one’s own home away from the family correlates with actually feeling independent, a key matter within this thesis. Curtice and Trew (2012) acknowledge that many PWLD witness non-learning disabled siblings moving from the parental home and are keen to follow suit, and easily accessible networks of support and care have been

essential in allowing these individuals to achieve a more independent life. For others, the *SAY? Consultation* (2012) found that living in shared accommodation remained the better option, although creating many of the same issues usually associated with sharing space and resources for those with and without learning disabilities. If PWLD are indeed the 'same as you', then they too face equivalent issues about moving out; funding this move, coping with housemates and so on. Through further support and increased understanding of barriers, PWLD can confront the idea of moving out in much the same way as do *all* young people moving out of the family home.

#### Security, Bullying and Independence

Though independent living was the marker by which success could be measured, it was recognised that living within community spaces was not always filled with positive experiences (*SAY? Consultation*, 2012:6). While most of the people asked felt safe in their own homes, bullying and harassment were also flagged up as an area of serious concern requiring attention in the future. Bowles and McGlaughlin (in Trew, 2010:59) call attention to the barriers which can hinder independent living for PWLD. Communication breakdown between professionals, parents, carers and PWLD, as well as the emotional impact of independent decision-making, a relatively new skill for many, proved to be the greatest barriers. Care professionals are seen to anticipate a rejection of support by PWLD, although Bowey and McGlaughlin (2005 in Trew, 2010:59) establish that PWLD are more realistic about their needs and level of support, creating an important point at which communication between all parties involved in care is essential. Moreover, Johnston and Martin (2005 in Trew, 2010:59), in their report on services in South Lanarkshire, find that some subjects, such as independent living, are taboo within families; with difficulties around "letting go" and "feelings of guilt" often limiting possibilities for, and feelings of, independence.

One way in which these channels of communication can remain open is through advocacy, consultation, choice and support for PWLD wishing to live a more independent life outside of the institution, as part of the family, in group settings or living alone. The original SAY? review (2000) was keen to pick out ways in which support networks might better run in order that choice and control could lie mainly with the individual. Through consultation, the SAY? review (2000:42) argued that PWLD could inform strategic planning, in turn allowing services to run effectively and more efficiently in the future. This proposal also recognised that such a goal would require clearer or simpler information and/or support to understand, plan and make decisions, but that the support should always reflect the intentions of the individual.

*How's it Going?* (Curtice, 2006), an interim review of SAY? found that independence was indeed a key concern for PWLD. With the SAY? *Scoping* report (2010:57) finding that 61% of PWLD were living in "mainstream accommodation", which includes the family home, the importance of advocacy and support services, both for PWLD and their carers/families, in tackling issues that might be emotionally charged becomes more apparent. Through in-depth interviews with PWLD and their carers/families, Curtice and Trew (2012:94) highlight the possibilities available when services are accessible, support is flexible and services are readily available. In this way PWLD have been able to lead lives *alongside* their medical requirements, as opposed to doing so *within* medical or hospital environments by pursuing interests, meeting friends, working, keeping fit and generally being part of communities in which they feel independent and safe. It has also been found, however, that this happy state of affairs is not a universal experience, with some finding services inflexible, restrictive and inaccessible.

*SAY?* (2000) tackled many of the complicated demands integral to providing a nationwide, appropriate service of support and care which could facilitate residential independence for PWLD, beginning to imagine a residential landscape truly outside of the institutionalised hospital setting. The resulting policy initiative failed quite to reach targets, although many of the recommendations, such as those discussed above, moved services and local authorities in a positive direction more able to provide appropriate accommodation, facilitate living independently and empower PWLD with choice and control. In reality, issues surrounding transport, work, education, health, age, advocacy, leisure and funding have also impacted upon the life experiences for those PWLD living within the community, and, though arguably a very positive step forward, *SAY?* (2000) remained a somewhat idealistic vision, one tough to implement in practice.

#### *The progression of deinstitutionalisation*

Ten years on from the publication of *SAY?* (2000), the Scottish Government planned a new ten year initiative, aiming further to expand on those initial recommendations and further to impact upon the residential landscape of PWLD. Through a focus on health and human rights, *The Keys to Life (TKTL)* – conceived in 2010 but only published in 2012 – proposes 52 recommendations, hoping to improve the everyday experience of those with learning disabilities throughout the course of their life. More so than *SAY?*, *TKTL* focusses on the life-span of PWLD, being aware that access to and need for services can vary as a person moves through life. Furthermore, it assesses how public bodies provide for PWLD in order to determine how they could best serve the learning disabled population. In doing so, it promotes the inclusion of those with learning disabilities in the creation and development of policies which affect them at both local and national levels. However, *TKTL* admits that the number of those living with a learning disability in Scotland is still largely an estimate,

and therefore it is questionable whether or not services can be prepared for a population about which the authorities they still know so little. Indeed, the work of the Scottish Learning Disability Observatory<sup>33</sup> has begun to fill a key knowledge gap in this area.

In a change from the policies regarding PWLD which proceeded *SAY?*, the latter went some way to advocating a ‘social model’ perspective, to the detriment perhaps of the more conventional ‘medical model’, a shift noted in Chapter 3. *TKTL*, on the other hand, arguably risks a reversal of this polarity, representing, in some ways, a shift back to a form of medical authority, notwithstanding the rights perspective which it also prioritises. The renewed ‘medical model’, or at least increased health focus, arguably sits uneasily alongside increasing support for the personalisation agenda (outlined earlier in Chapter 3). This stance somewhat diminishes the ‘social model’ underpinning of *SAY(?)* and its insistence on prioritising independent living. *TKTL* seems instead to replace the focus of concern on health, effectively arguing that all issues for PWLD can be approached and brought to resolution through attention to health. Though undeniably integral to experiences of learning disabled life, it remains but one facet among many which impacts on experiences of decision-making, belonging and opportunities for movement of PWLD; a point made clear by key contribution by Oliver (1990), among others.

A large portion of the *TKTL* policy document outlines the issues and recommendations surrounding ‘independent living’, suggesting that PWLD should have the same “freedom, choice, dignity and control” as other citizens (*TKTL*, 2013:54). As such, services should, in theory,

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<sup>33</sup> The Scottish Learning Disabilities Observatory (SLDO) represents a joint effort between the Institute of Health and Wellbeing at the University of Glasgow and the Scottish Government, with the aim of producing high quality evidence to support disability policy and practice. By working alongside various partners, the Observatory aims to build and sustain increased visibility for PWLD in datasets, particularly health-related datasets, so resulting in better representation within the population as a whole (<https://www.sldo.ac.uk/>).

provide practical assistance and support where needed in order to facilitate the leading of an “ordinary” life (*TKTL*, 2013:54). The use of the term ‘ordinary life’ is a somewhat vague terminology for what can in fact be a hugely complex set of issues. The document is not clear about what this ‘ordinary life’ should entail, while loosely suggesting that “75% of [PWLD] thought that they had enough opportunities to do the things they wanted with their lives” (Curtice 2006 in *TKTL*, 2013:54). This claim fails to outline where those opportunities arise, both geographically and economically, and so it is difficult to see quite how these recommendations may shape service provision in the future. Of particular importance have been the barriers to community engagement identified by Curtice (2006), which suggests that a lack of support staff, inflexibility of support and lack of transport all play a significant role in reducing how PWLD interact within their communities. While *TKTL* is keen to highlight the hurdles which must be overcome, there seems to be no specific plan as to how this objective will be met, other than through the partners of the Independent Living Programme<sup>34</sup> signing a “revitalised shared vision statement” in March of 2013 (*TKTL*, 2013:55), representing a shift in thought, if not in practice.

UK welfare reform is tackled fleetingly within *TKTL* in relation to independent living. It points out that the economic downturn<sup>35</sup> continues to have serious impacts for how people on low incomes can

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<sup>34</sup> The Independent Living Programme represents a partnership of Scottish Government, COSLA, NHS Scotland and the Scottish Coalition for Independent Living. This group promotes and supports the need for real change which positively impacts of the lives of disabled people (*TKTL*, 2013:55).

<sup>35</sup> Sparked by the collapse of a housing bubble in the US, the financial crash of 2007-2008 plunged many Western nations, including Britain, into economic recession, resulting in the introduction of austerity measures (Clarke, 2015). Described by Blyth (2013:2) as the “reduction of wages, process and public spending” in order to cut “the state’s budget, debts and deficits”, the impact of the recession was felt most keenly by those who most required state support. In 2012, Goodley reported that disabled people have lost £9 billion in welfare support alone, equating to an annual loss of £2000-3000 per household, not to mention parallel cuts to health care and support services.

manage their daily living costs. As a result, the *TKTL* policy outlines the need for a cash injection for those agencies which help people who are most affected by UK benefit cuts, promising a total of £5.4 million over the next two years to agencies such as Citizens Advice Scotland. While it is important to have the correct support in place, this kind of support does not seem solely focussed on PWLD and so raises concerns as to whether agencies are fully prepared to support the individual needs of PWLD. A further concern is the planned closure of the Independent Living Fund (ILF) by April 2015, placing the responsibility of finances directly in the hands of the Scottish Government, who launched a consultation in order to “seek views” on the best method of distributing those finances (*TKTL*, 2013:55). These changes have since been rolled out, affecting PWLD differently across geographical boundaries as resources are further localised and unevenly distributed (Furner, 2016). *TKTL* argues that the planned reforms indicate a simplification of interactions between the government and those who require welfare, although it is uncertain whether or not this is likely to allow PWLD to continue to lead the lives of their choosing.

*TKTL* arguably marks a crucial shift in the balance of roles and responsibilities between local and central government, and Hall and McGarrol (2013:691) propose that this shift has been evidenced by a seeming “hollowing out” of power and responsibilities from the central state, and a “filling in” of these powers at other governmental scales and through different organisations. Shaw and MacKinnon (2011) conceptualise such a rescaling as both “structural” and “relational”, in that new structures and organisations have been developed alongside new “working cultures” involving interaction between the state and other actors. In the PWLD sector, it has represented a further re-scaling of personalised care as witnessed through the UK government’s ‘localism agenda’ which, in line with

ideas of the 'Big Society'<sup>36</sup>, has involved the re-allocation of power and responsibilities from central government to individuals, communities and the private and voluntary sectors. This re-allocation recasts local authorities as 'enablers' of social care as opposed to providers, so 'filling the gaps' in service provision. This change, unsurprisingly, has been heavily criticised as the "final act of the roll back of public services" (Hall and McGarroll, 2013: 691), whereby the onus will fall on to local communities to run required services threatened by closure, resulting in the uneven landscapes of care and service provision and quality currently in evidence.

*TKTL* also looks at the role of day centres in the daily and community lives of PWLD. Where previously *SAY?* (2000) encouraged local authorities to rethink the role of the day centre in favour of a 'resource base' model, the former being seen as still redolent of an institutional model, *TKTL* reported that the numbers attending day centres in the 13 years since *SAY?* had decreased, coupled with an increase in those accessing alternative opportunities. This rebalancing was also tied to changes in how funding was allocated to individuals, with the Social Care (Self-Directed Support) (Scotland) Act 2013, discussed earlier, altering the way in which services for PWLD are now commissioned (*TKTL*, 2013:17) and so encouraging PWLD and their carers to take more control over which services are used and when. Arguably, this policy change does marks an important, even decisive, 'personalisation' of services, but what will it actually mean for day centres who already struggle to provide a service with the funds available to them currently?

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<sup>36</sup> 'Big Society' was a flagship policy in the 2010 Conservative party general election manifesto and the subsequent Conservative-led coalition government. In order to tackle the perceived "selfish individualism" and "passive dependency" (Williams *et al*, 2013:2799) of a "Broken Britain" (Cameron, 2009), 'Big Society' supposedly offered public service reform, decentralisation of power and more community activism and social enterprise (Clarke and Cochrane, 2013).

Another tension arises here in the continuing sense that care solutions do not lie in 'bricks and mortar', in physical structures housing collective learning disabled provision, so prompting the scepticism about day centre spaces, not just about residential accommodation. Yet, this presumption must be coupled with, perhaps grudgingly, a realisation that, for many PWLD, the day centre remains the *only* way of allowing spaces outwith the home where they can interact with others and partake in activities of interest to them. There is an understanding that there needs to be a comprehensive network of day services and resources available which meet needs across the learning disability spectrum, but *TKTL* is not specific about how these opportunities should appropriately be funded. It merely suggests that services and staff should continue to develop person-centred choices which allow PWLD to undertake activities meaningful to them. Moreover, the policy states that services should continue to provide community-based models of care and support to move PWLD into alternative opportunities. The ways in which this movement should be achieved, nevertheless, are not made clear.

#### *Employment and TKTL*

Furthermore, *TKTL* suggests that the goal for those with learning disabilities *should* be employment and meaningful activity. The use of the word 'should' is problematic. There should, of course, be opportunities to enter into employment as and when PWLD wish to do so, but such life goals cannot be instilled upon all individuals, and certainly not all of those in the wider PWLD constituency. The use of this language appears counterintuitive considering the weight given within much of the document to ensuring that services reflect the needs of each PWLD, ones acknowledged to be extremely variable. The policy also calls for more collaboration between different services and agencies, again insisting on organisation at the local level through local care agreement packages. A lot of pressure is placed on day

services to liaise with education, training and support agencies to provide a one-stop-shop which accommodates everybody and every eventuality, something increasingly unlikely even in the financial climate of the policy. As a result, if too few PWLD chose certain day opportunities, it can result in the closure of more day centres, in turn, having negative impacts on the costs of certain services, perhaps rendering them unusable for certain PWLD.

The 'where' of services is highlighted as important, with South Lanarkshire and Renfrewshire councils both given specific mention for their service provision. Within these areas, services are provided within leisure centres, allowing easier access to healthy activities within 'normal' spaces. This experiment is seen as a move forward in breaking down the barriers associated with encountering PWLD in public places, seemingly allowing PWLD to feel part of the community in which they live.

It can be noted throughout *TKTL* that choice and control are deemed central to independent living, not just in the 'bricks and mortar' of a house, but through the connection to the community and ability to use a home-space as a starting point for the other things which impact on daily lives. It is therefore important to remember that financial, support and social factors play a significant role in the overall experience of living independently, and so may also impact on how PWLD view 'home' and experience 'decision-making'.

#### *Housing and TKTL*

Turning to the subject of housing more specifically, *TKTL* considers 'home' to be at the heart of independent living. Importantly, these homes should be in the correct location and provide the right type of housing for those who need to coordinate care and support with access to services and day opportunities; and the policy points out that the majority of PWLD already live in 'ordinary housing', that is to

say not in hospitals or care homes. *TKTL* indeed displays a continued antipathy to hospital and long-stay institutional settings, reiterating the compulsion to ‘do away’ with the asylum, rebounding into suspicion of any static space of care provision, including day centres. Home-spaces for PWLD are envisaged either as remaining in, or returning to, the ‘family home’, with the balance between institutional and non-institutional spaces of independent living largely played down. Arguably, it is the reality of finding such places for PWLD about which *TKTL* is most vague and where the most work is required. Just how those with learning disabilities access and maintain safe and supportive housing remains the difficulty, challenging how decision-making, movement and belonging can be integrated to create an ‘independent reality’ in which PWLD are indeed happy and fulfilled personally, socially and in terms of health.

The *SAY?* review (2000) found, unsurprisingly, that one-size does *not* fit all when it comes to housing for PWLD, and *TKTL* now supports a need for a thorough examination of individual needs and the ways in which these needs can be addressed in order to provide appropriate housing. The Housing (Scotland) Act 2001 states that local authorities must provide Local Housing Strategies which assess the housing need and demands of the local constituency. As such, local and national governments have agreed that these strategies should be at the centre of the planning and development of new housing. Jointly with the Convention of Scottish Local Authorities<sup>37</sup> (COSLA), the Scottish Government has agreed to fund a review process for local housing strategies and *TKTL* suggests, in Recommendation 29, that these reviews should also include PWLD and their carers in the development

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<sup>37</sup> COSLA promote themselves as a political decision making system, which is designed to ensure that councils are at the heart of decision-making which impacts on their communities, essentially aiming to allow local government to react quickly and make changes where appropriate for specific local communities ([www.cosla.gov.uk](http://www.cosla.gov.uk)).

of future housing plans. This proposal goes some way to recognising that ‘independent living’ encompasses a variety of different housing and support situations, further emphasising that living independently is precisely *not* living without adequate support.

*TKTL* further suggests that housing adaptations can be a cheaper housing option which supports a more flexible lifestyle, hopefully enabling PWLD to live within homes and communities where they are comfortable and have not been forced into relocation. *TKTL* is also keen to flag up the financial benefits of housing adaptation<sup>38</sup>, with changes being more cost effective than residential care home places. It is suggested that suitably adapted home-space reduces the risk of serious injuries and therefore may lessen the need for lengthy and costly hospital visits. Using the example of Housing Options Scotland<sup>39</sup> (*TKTL*, 2013:62), *TKTL* describes how organisations are able to act on behalf of families to find suitably adapted shared accommodation in an area which suits both the PWLD themselves and their families, allowing a 24-hour care package to be put in place which supports PWLD to live their everyday lives. Once more, the policy fails to give details about the costs of using such services, nor details of how these services might be funded.

The policy also outlines a different kind of supported accommodation in what are termed “Camphill Communities”<sup>40</sup>, of which there are 11

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<sup>38</sup> These housing adaptations can include, but are not limited to, the provision of emergency cords, epilepsy plates which can detect night time attacks, railings inside and outside the home, and shower seats as and where required by the individual and their co-morbidities.

<sup>39</sup> Established in 1997, Housing Options Scotland is an organisation which aims to work with, and on behalf of, disabled people and their families, providing advice and help regarding home-ownership, social housing and private rent agreements. Working across 32 local authorities, Housing Options Scotland creates person-centred housing options, also providing a peer service to allow PWLD to talk to others in similar positions. The organisation is currently in partnership with the Scottish Government, working on a scheme which aims to empower PWLD with the tools to influence, inform and engage with policy ([www.housingoptionsscotland.org](http://www.housingoptionsscotland.org)).

<sup>40</sup> [www.camphillscotland.org](http://www.camphillscotland.org)

throughout the UK supporting 400 PWLD (*TKTL*, 2013:62). These communities are said to promote a “relationship-based” approach which utilises everyday living situations in order to allow PWLD to develop the skills which may enable them to lead a more independent life. Those with learning disabilities are given the option to live within communities, in ‘family’ homes or to use them as day centres where they are encouraged to work and learn amongst others with learning disabilities in a ‘family setting’. Work is an essential element of Camphill living, and facilitators are keen that PWLD are able to make a living wage for themselves through social enterprise, building ties between each other and the wider community, and allowing PWLD to feel a sense of achievement. *TKTL* (2013:63) reports that families of those with learning disabilities also feel secure in the knowledge that their family members are being cared for physically as well as mentally, in a space which provides them with support and opportunities for personal development. These ‘new’, semi-institutional, residential spaces appear as minor reinventions of the sort of restorative, ‘village asylum’ mentality displayed by the very earliest incarnation of the asylum. Communities such as this received funding attention throughout 2013, although the Camphill brand itself was forced to cleave a new, Scotland-only, route in order to meet the social vision outlined by the Scottish Government, one very different from the approach to care in England and Wales. Where these communities differ from more traditional associations of ‘village asylums’ is the continued development of links with the wider, non-learning disabled community in which residents and day centre users are encouraged to participate. Although potentially insular, the break away from Camphill branches in England and Wales has forged a Scottish Camphill network less focussed on residents’ productivity as learning disabled working citizens, and more on the development of skills and the encouragement which breeds confidence and self-

worth; both feelings with which those spoken to in this thesis continue to struggle.

As with all residential opportunities, access to day centres and places of interest are key components of how suitable is a home. It is important, then, to think about how transport impacts on PWLDs' ability to get around the areas in which they live. *SAY?* (2000) found that the favoured method of transport for PWLD is bus, and *TKTL* (2013:64) suggests that, in order to be truly independent, PWLD require public transport to be accessible, affordable and, crucially, available. Funded by the Scottish Government Equality Fund, Share Scotland intends to pilot a 'Journey to Success' project through which staff from Share Scotland will be trained as 'accredited travel trainers'. They will then, in turn, work with 16 PWLD from across Scotland (*TKTL*, 2013:63). Over a 24-week period, these 16 PWLD will be supported to gain the skills necessary to plan and carry out journeys using public transport. Furthermore, local transport companies will be provided with information on how best they can support learning disabled passengers. Following on from the potential success of such schemes, *TKTL* suggests that local authorities may be interested in funding such projects in the future. The policy posits that implementation of such schemes would reduce the pressure on social work services to provide costly taxis, special buses and escorts for PWLD. Sadly, such schemes have as yet failed to materialise from local councils, with many charities, such as Enable and Deaf Blind Scotland, picking up where local authorities have arguably failed, developing new initiatives and even smart phone applications which more easily allow PWLD to explore, and feel confident in, their local communities and beyond.

Also helping PWLD to discover opportunities in their area are Local Area Co-ordinators (LACS), a role first introduced in *SAY?* (2000). The work of LACs focuses on creating individually tailored relationships between PWLD and their communities, providing a coordinator who

is able to act as a bridge between individual PWLD and the community groups, associations and public services which are best suited to their wants and needs. The role is purposely flexible, allowing PWLD to use the service as much or as little as they need throughout their lifetime, the ultimate goal being that PWLD become empowered decision-makers, with the confidence and connections eventually to reach their goals *without* LAC input. Yet, there are still some localities within Scotland where this service is not offered, and so *TKTL* (2013:66) proposes a review of the contribution of LACs to independent living, with the view of expanding the service. Through a one-to-one support service like LAC, it is clear to see how PWLD can be supported to live more independently within homes and communities where they are comfortable, feel safe and are happy. Within the highly contested landscape of UK wide localism favoured in England, Hall and McGarroll (2012) argue that Scotland has begun to carve out its own 'progressive localism' which situates place as active in the reconstruction of care in a landscape of public sector roll backs and austerity (Featherstone *et al*, 2012). In these spaces, innovative forms of care and practice can flourish beyond the ever-reducing formal and individualised funding of care services (Hall and McGarroll, 2013), so making room for grassroots development and activism. Unfortunately, some four years after the release of the original policy, there do remain these huge geographical discrepancies in where LAC can be accessed, an issue which *TKTL* failed to tackle directly and one recognised by Hall and McGarroll (2012). Of those PWLD interviewed within this thesis from across GG&C, only one had regular and positive contact with a LAC, certainly not the numbers envisaged by *TKTL*.

Many of the recommendations put forward by *TKTL* do begin to address some of the main issues which impact upon PWLD living independent *and* contented lives. However, the policy is often vague regarding not only how these changes should be implemented, but

also how these changes should be funded. The move away from institutional settings has been of benefit to most PWLD, but it is clear that there is still some way to go in providing suitable homes in which PWLD can feel independent, safe and supported. While self-directed support seems like it provides a more flexible approach, compared to locking learning disability investment into the concrete and personnel of large (or even not-so-large) residential institutions, it must remain careful not to install a 'supermarket service' ethos where competitive pricing between service providers impacts on the affordability or level of service given. Moreover, the policy framework does not seem to contain a contingency plan for those day centre service providers who cater for a smaller, but no less important, population of PWLD. Furthermore, Hall (2011) states that the refocus of care away from communal spaces, such as day centres, and into the private and public spheres of home and community, disrupts the types of care available for PWLD. Building on this, Needham *et al* (2015) argue that self-directed support brings up questions of accountability, both in how the money is controlled by PWLD and how the buying of care can remain a transparent process which continues to meet the needs of PWLD as their circumstances evolve and change. As such, Mol (2008) suggests that care is complex and inter-relational, requiring a constant dialogue between PWLD, carers, families and government bodies rather than simply becoming a one-off transaction. Hall's (2011:599) work proves that there is a "sustained demand for wider networks of caring and relationships of interdependence" which could more readily provide a personalised space for caring, clearly not set-out by Self Directed Support. As set out more fully in Chapter 5, this has keenly felt consequences for the types of decisions PWLD are actually able to make.

This issue further highlights the gap between providing flexible services which suit each individual with learning disabilities, and

obtaining appropriate funding to allow such services to remain open, a gap which has since clearly been detrimental to the running of many day centres. Indeed, 2013 saw the closure of three main day centres in Glasgow alone (Berryknowes, Hinshaw Street, and Summerston), resulting in the reduction of available day centre places from 520 individuals to just 200 ([www.ldascotland.org](http://www.ldascotland.org)), leaving many without the care and support provision required. Arguably, the decision by Glasgow City Council to close these predominantly learning disabled spaces actually reduced the opportunity for choice, control and independence, directly opposing the main ethos of *TKTL*.

The *TKTL* document itself appears rushed, with many tell-tale signs including poor spelling, formatting and referencing. This issue leaks over to the content of the policy which often leaves recommendations underdeveloped or relies heavily on successful work undertaken by other organisations. Many of those recommendations which have been taken forward have done so through charity and advocacy groups, as public funding remains either underwhelming or simply unavailable. Overall, *TKTL* reflects the complexity of finding suitable homes which enable PWLD to live independent lives while still being supported for their needs, all within a tight budget. Although *TKTL* is perhaps not directly the keys to solving the issue of where PWLD can call home, not 'the key to life' it certainly brings to the fore those issues which must be tackled in order to allow PWLD the freedom, choice, dignity and control which would allow them to lead the life which they would ideally wish to live.

***Physical geographies: how do these landscapes look now?***

Both *SAY?* and *TKTL* have undoubtedly been pivotal in putting into action much needed reform regarding the residential 'where' of PWLD in Scotland. Without doubt, these policies have shaped a move away from the institutional setting of the hospital as the site of both care

and home, changing the focus from the institution to the needs of the individual. Quite how this move has changed the physical landscape of learning disabled residential spaces and experiences nonetheless remains unclear, and so the chapter now turns to a mapping of these 'new' residential realities. Through closer engagement with the residential whereabouts of the learning disabled population, a better understanding can be gained regarding the geographical spread of PWLD and, therefore, the potential pitfalls and positives of a move 'out of the asylum'. The thesis therefore turns here away from policy by mapping out those places within the study area of Greater Glasgow and Clyde where people with learning disabilities actually live with the aim of visualising those policy changes outlined in the chapter thus.

#### *Cluster mapping*

Figure 11, overleaf, gives an initial bird's eye view of Scotland and the Western Isles, including the current (though ever evolving) 14 regional NHS Boards which represent 27,218 PWLD ([www.SCLD.org.uk](http://www.SCLD.org.uk)). Of interest within this research, is the area bounded by NHS Greater Glasgow and Clyde (GG&C); though one of the smallest regions by area, NHS GG&C represents 1.2 million people – of which 5079 have identified learning disabilities ([www.SCLD.org.uk](http://www.SCLD.org.uk)) – making it one of the largest NHS operations in the UK and the largest in Scotland (Scotland's Health on the Web, 2015). Further broken down, GG&C is constituted of seven different local authorities<sup>41</sup>, allowing a probing of some of the difficulties presented by these uneven landscapes of economy and social disparity.

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<sup>41</sup> Authorities contained within GG&C include Inverclyde, Renfrewshire, East Renfrewshire, Glasgow City, East Dumbartonshire and West Dumbartonshire. Parts of South Lanarkshire (Rutherglen and Cambuslang) are also included, but from 2014 onwards have been going through the slow process of moving authority boundary to NHS Lanarkshire, but both Rutherglen and Cambuslang are included in the above data ([understandingglasgow.com](http://understandingglasgow.com), 2015).

Figure 11. provides a base map upon which information with regards to the learning disabled population can be built; and, using a sample of postcode data provided by the NHS GG&C Learning Disabilities Database<sup>42</sup>, the story of post-institutional residential spaces begins to emerge. The postcode data used refers to those PWLD who have accessed an NHS site and have been identified as having a learning disability by their GP; it is therefore not a comprehensive list of everyone with learning disabilities living in the GG&C area, but nonetheless offers insight into the numbers and spread of PWLD living within this boundary.



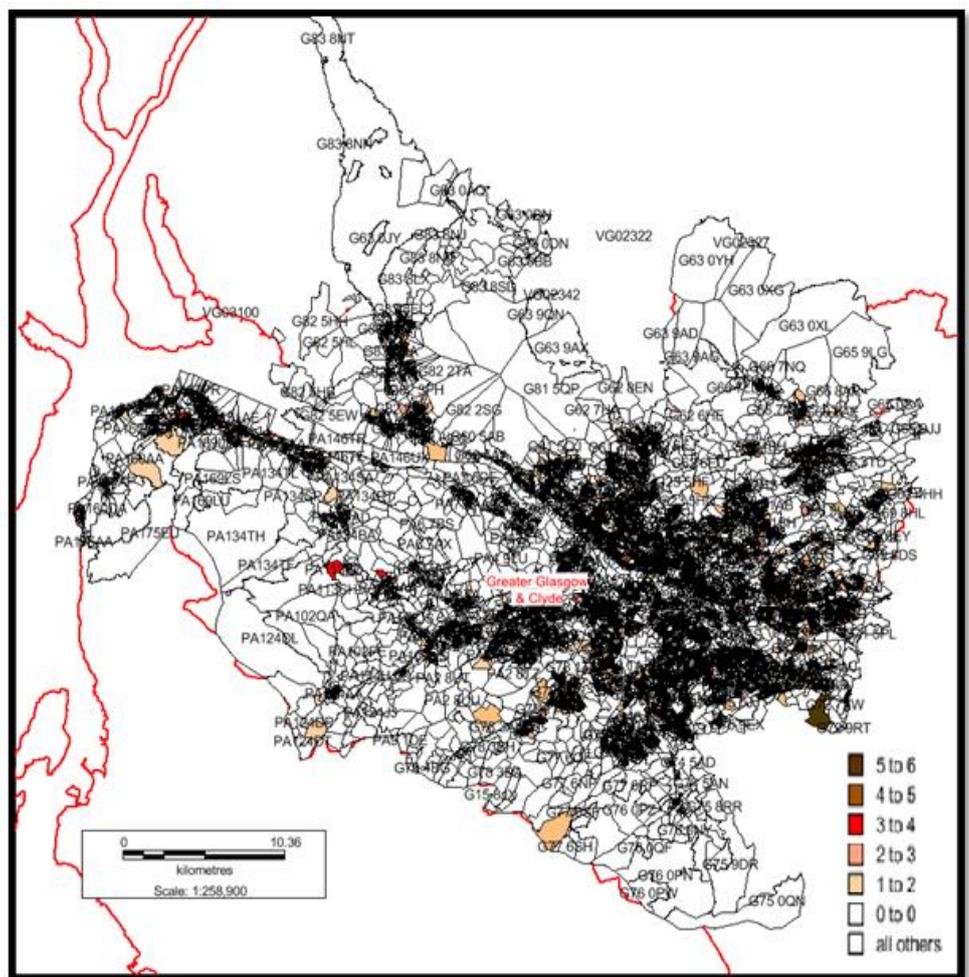
**Figure 11.** Showing current NHS boundaries for mainland Scotland and The Western Isles.

<sup>42</sup> Access to this database was granted through NHS GG&C, supported by Professor Sally-Anne Cooper and deemed a suitable use of data by the NHS MREC Ethics System (see Chapter 3).

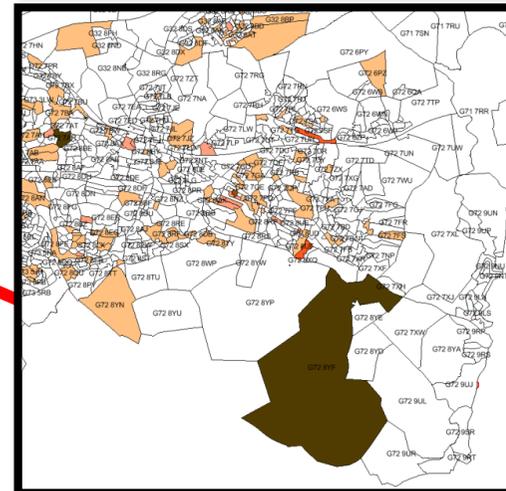
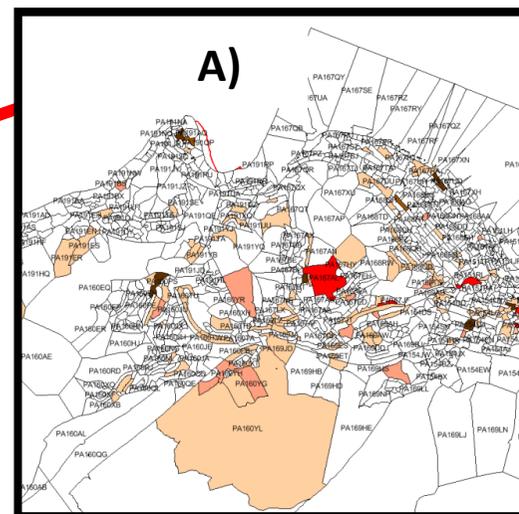
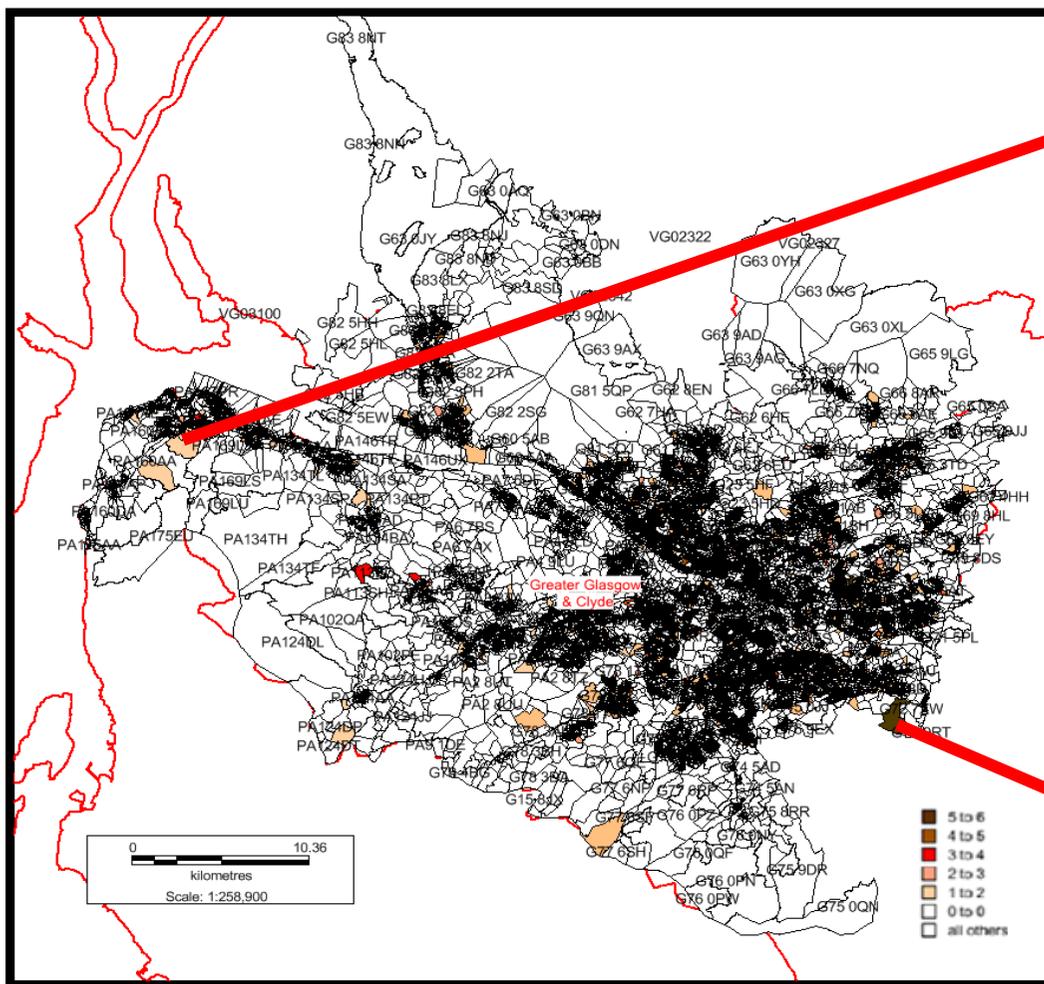
Plotting this postcode information onto the surface of the GG&C map allows spatial densities of PWLD easily to be seen, as shown in figure 12. below. As the density of PWLD living within each postcode boundary rises, so the colour of that boundary moves from white to dark brown, allowing the viewer easily to identify those postcode boundaries in which most PWLD live. This map generally reveals the spread of PWLD across GG&C, and it can be seen that, since the closure of long stay institutions, there are still many 'hotspots' in which up to six PWLD can be found living within the same residence, perhaps not what one might expect to find after the admonishments of *SAY?* and *TKTL* as leading policy frameworks on the 'where' of learning disabled residency. Working between figure 12. and the GG&C Learning Disabilities Database, basic information could be ascertained regarding the gender of the individuals living within that postcode and, using Google Search engine, certain postcodes of high density could further be investigated to reveal residency types. Geographically speaking, the more condensed and most highly populated postcodes showing PWLD are those found in inner-city spaces such as Glasgow City, supporting SCLD (2014) findings which state that three quarters of PWLD live in densely populated urban areas. Of those people with learning disabilities known to local authorities, the majority (6822 people) live in the 40% most deprived areas of Scotland (SCLD, 2015), meaning that there is an over-representation of 270 PWLD/1000 within these areas, as opposed to an average of 190 non-learning disabled people/1000. The high prevalence of those with learning disabilities living in deprived areas raises questions regarding the available funding for care and community services allowing PWLD to lead interactive and meaningful lives in which they feel that they have choice and control.

#### *Areas of interest*

Of particular interest are those excerpts highlighted by figures 13, 14 and 15 below showing the areas of Greenock and Cambuslang respectively, two relatively peripheral or suburban parts of the overall metropolitan district. Revealed within these bounded spaces are group homes, care homes, Camphill Communities, Sheltered Accommodation and shared homes run by a number of different care companies and charities, some assumedly also representing private tenancy agreements set up through negotiations between PWLD, parents/cares/guardians/advocacy groups, although the data is unable to reveal this information with any clarity.



**Figure 12.** Showing how many PWLD live within a certain postcode by range. Presented in full in Appendix 6.



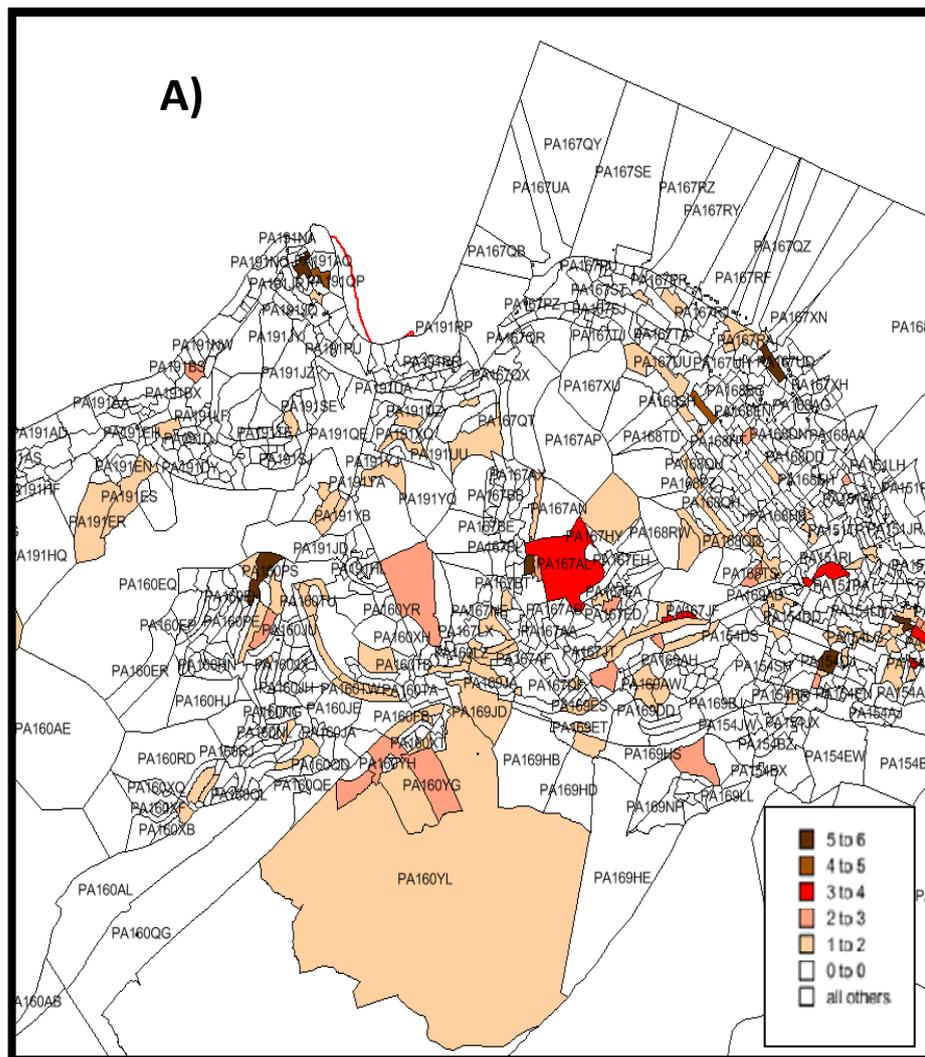


Figure 14. Showing section A excerpt from Figure 13. Reproduced in Appendix 7.

Figure 14. above highlights the Greenock area of GG&C, where it can quickly be noted that there are several dark brown areas which may be of interest, indicating that five or six PWLD live within this particular postcode. Further drawing attention to postcode PA16 7NX found centre right of figure 14, cross-referencing with the GG&C Learning Disability Database shows that this postcode is home to three females and three males with learning disabilities. Upon further investigation, the residential space represented by this postcode relates to *ABC Supported Living* run by the charity Quarriers<sup>43</sup>. This scenario was the case for many of the more densely learning disability-populated postcodes throughout the GG&C area, with many

<sup>43</sup> <https://quarriers.org.uk/services/abc/>

such postcodes hosting charities who specialise in community care, involvement and support for those with learning disabilities, such as Voyage Care<sup>44</sup>. Table 3 below shows those residential providers for PWLD most easily identified and available within GG&C as experienced by those within the GG&C database.

#### *Accommodational options within the study area*

Although in no way comprehensive, the array of available accommodational options, funded privately and through charitable organisations, begins to paint a picture of the jigsaw of residential options required to fill the gaps left behind by losing an older heavy-duty institutional model of care and residency with the rolling back of state provision in this area. It would seem, at this stage, that many PWLD have simply been decanted into new, smaller but arguably still institutional spaces in which their needs can be met, with some residential spaces even describing themselves, tellingly perhaps, as 'pre-independent living' ([www.voyagecare.com](http://www.voyagecare.com)). Perhaps this situation also highlights the failings of both *SAY?* And *TKTL* to recognise and establish a middle ground between 'in' and 'out' of the institutionalised hospital setting, ignoring to some degree the need for many PWLD, especially those who had spent many years within an institution, to adjust to the idea and practice of a more independent lifestyle, should that be something ever sought in the first instance. Although appreciating the need for these residential changes to come about slowly, the reality seems to have focussed more on matching available finance with 'somewhere to go', rather than establishing precisely how transitions could be met. Invariably, without the patching together of the various charities and housing associations mentioned in Table 3, residential spaces for PWLD out of the

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<sup>44</sup> Voyage Care are a UK wide charity who aim to offer person-centred care and support in a number of residential settings, offering services which include supported living, outreach support, pre-independent living and residential services. ([www.voyagecare.com](http://www.voyagecare.com)).

institutional setting may have meant simply a ‘return’ to the family home, where burdens of care and pressure to support and provide could be exacerbated.

<b>Residential Providers for PWLD within NHS Greater Glasgow and Clyde</b>
Linstone Housing Association ( <a href="http://www.linstone.co.uk/">http://www.linstone.co.uk/</a> )
Link Housing Association ( <a href="https://linkhousing.org.uk/">https://linkhousing.org.uk/</a> )
Flemmington Care Homes ( <a href="http://www.flemingtoncarehome.co.uk/">http://www.flemingtoncarehome.co.uk/</a> )
Blackwood Homes ( <a href="https://www.blackwoodgroup.org.uk/">https://www.blackwoodgroup.org.uk/</a> )
Voyage Care ( <a href="http://www.voyagecare.com/">http://www.voyagecare.com/</a> )
KEY Housing Association ( <a href="http://www.keyhousing.org/">http://www.keyhousing.org/</a> )
The Richmond Fellowship ( <a href="http://www.richmondfellowship.org.uk/">http://www.richmondfellowship.org.uk/</a> )
ABC Supported Living ( <a href="https://quarriers.org.uk/services/abc/">https://quarriers.org.uk/services/abc/</a> )
McCarthy and Stone ( <a href="https://www.mccarthyandstone.co.uk/">https://www.mccarthyandstone.co.uk/</a> )
Quarriers ( <a href="https://quarriers.org.uk/services/abc/">https://quarriers.org.uk/services/abc/</a> )
MacFarlane Homes Ltd ( <a href="http://mcfarlanetrust.org/">http://mcfarlanetrust.org/</a> )
Johnstone and Paisley Supported Living ( <a href="https://quarriers.org.uk/services/abc/">https://quarriers.org.uk/services/abc/</a> )
Hanover (Scotland) Housing Association ( <a href="https://www.hanover.scot/">https://www.hanover.scot/</a> )

**Table 3.**housing providers in the NHS GG&C Learning Disability database.

Although the map is able to give an indication of the types of residency now being experienced by PWLD outside of institutions, meaning the old asylums or hospitals, it gives very little information with regards to the specifics of the living situation of these individuals. It is, at times, unclear from the postcode information whether or not these particular localities are hosting group homes, housing complexes, sheltered accommodation or simply shared tenancy. The residential use of some postcodes of interest are perhaps more obvious, however such as that shown in figure 15 below Figure 15 shows the



Flemington House, raises question about the experiences of those PWLD living with multiple others with such varied personal and social needs. Many of the other facilities emphasised by the map are also care homes which market themselves as 'age specific' housing, catering for older people rather than specifically for those with learning disabilities. What cannot be surmised from the postcode data available is whether or not these individuals are living in care homes designed for the elderly because they are themselves elderly, or because there is no other facility which is able to cater for their needs. Or, is it symptomatic of social understanding or care within a certain time period, which favoured the institutionalisation of those with learning disabilities; a routine which is perhaps difficult or upsetting to break for those involved? Perhaps, indeed, many of the residents who remained within institutional settings as the ideologies and processes of deinstitutionalisation took hold were elderly. It is then fair to suggest that those individuals, and their resulting residential locations, embody policies more readily associated with the ageing population than a specifically learning disabled one and quite possibly also represent a population of elderly PWLD who simply do not have surviving family members to step in to provide care.

Some areas, such as Elderslie in Paisley, show a locational clustering of group residencies or care homes within the wider postcode district, such as PA5<sup>45</sup> in the case of Elderslie. Although the map is easily able to show this clustering, it poses yet more questions as to why this clustering is the case. It may be that the services in this area are well-funded and well-developed, therefore attracting charities and housing associations, even creating what Wolch (1980) might term a 'service-dependant ghetto' of PWLD. Moreover, closer proximity to these

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<sup>45</sup> The first two letters of the postcode relate to the town, followed by a number which focusses on the district. As such, using only the first 3 letters allows individuals to stay anonymous but allows data trends to be witnessed across and between postcodes.

services may encourage some PWLD to feel comfortable using services if and when necessary, perhaps making it easier for organisations to integrate PWLD within the community setting. Using Community Health and Wellbeing profiles collated by Glasgow Centre for Population Health ([www.gcph.co.uk](http://www.gcph.co.uk)), it can be seen that many of the areas populated by charities also represent those communities in which house prices are lower, and so properties are more affordable, and, where local populations which show least resistance to the building of 'noxious' facilities like care homes (Takahashie *et al*, 2007; Smith and Hanham, 1981) . In the case of Elderslie, Community Health Profiles suggest a relatively low population of elderly residents, hence suggesting that group homes here are catering mainly to the learning disabled population. Average house prices of £118 000, though, would suggest that private funding may be more readily available in this area than in others with regards to private housing and shared tenancy. In contrast, the Greenock area of GG&C shows a positive correlation between social deprivation and numbers of PWLD living within that area. Such areas display a smaller number of learning disabled residents living within each postcode, so suggesting that these homes are privately owned or local authority funded, but, again, the exact residential situation is difficult to ascertain at the scale provided by general mapping and profiling. Without more information from those with learning disabilities themselves detailing their own personal residential histories and financial situations, it is difficult to draw any conclusions which can be generally applied to the learning disabled population as a whole.

#### *Proximity to asylums of old*

Aside from population demographics, it is not farfetched to assume that a higher number of PWLD may also be more heavily represented in those postcodes which surround de-commissioned long-stay institutions. The services and support networks which may have been

created in the immediate areas could, arguably, continue to be used long after the closure of the institutions themselves, so rendering these locations more desirable as 'familiar' spaces and places. Relating to the most prominent learning disability long-stay institution within GG&C, although by no means the only one, Figure 16., below displays the postcodes potentially impacted upon by Lennox Castle Hospital, itself located in postcode G66 7LD. A three mile buffer zone was selected, with Lennox Castle as its centre, and this buffer was selected as it was estimated that three miles was around a one hour walk from the original site of the hospital, a distance close enough to the facility to utilise the networks which may have been in place when the hospital was still in use, and which may have survived in some form subsequently. Many of the specific localities here which appear to have no residents with learning disability living within them (white in colour) represent hillside and farmland in which there are very few private properties, the site of the original long-stay institution having been chosen, like many asylum spaces, for its rural and tranquil setting. The physicality of the landscape therefore impacts on the clustering and it can be seen that there are a number of PWLD living within the Lennox Castle Hospital buffer zone. It cannot be argued, even so, that this particular zone has a higher concentration than those postcodes which fall outside of the buffer zone. Indeed, the areas to the east and west of the buffer zone seem to offer a higher concentration of PWLD, suggesting some movement from larger to smaller scale institutions impacted by a number of social, economic and cultural motivations which cannot be touched upon through mapping alone.

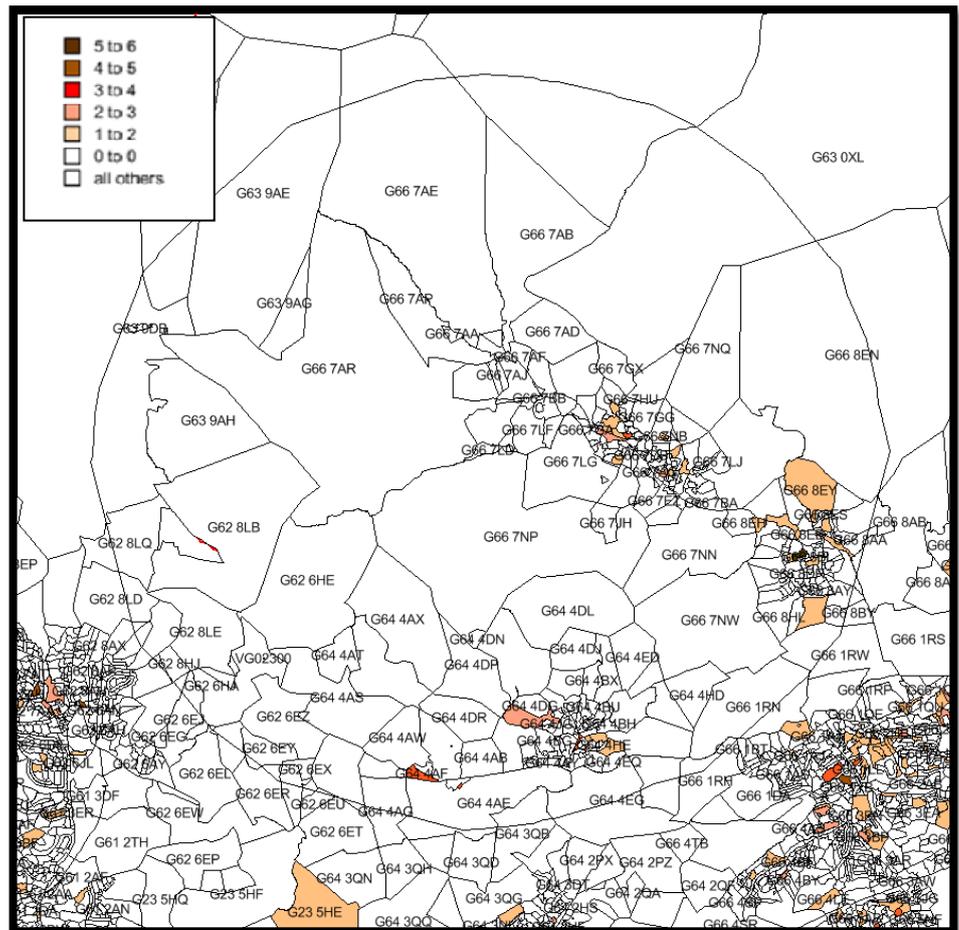


Figure 16. Showing buffer around G66 7LD – Lennox Castle Hospital

While mapping is a helpful exercise in allowing a closer understanding of the overall region in which the research takes place, it is more usefully utilised as a springboard from which more questions arise. It provides a useful engagement with the postcode data selected for the study, allowing the relatively quick investigation of those areas in which the highest concentration of PWLD live. Data such as this are able easily to show that PWLD have moved out of the traditional long-stay hospital institutions as recommended by both *SAY?* and *TKTL*. The clusters of PWLD shown in Figure 16. suggests that these spaces have been replaced at least partly by care home and group home settings, as might have been expected. Largely unaccounted here are the living situations of those PWLD who appear on their own in lighter shades on the map. Without engaging with these individuals face to face, it is difficult to say anything about their current living situation and so the

maps leave them wholly underrepresented. The maps hence offer a disembodied snapshot which requires interaction with those whose residential lives I am trying to investigate, in order to add texture and make sense of their stories and allow me to understand why they do live where they do, and how they feel about these spaces which they call home.

#### *A closer look*

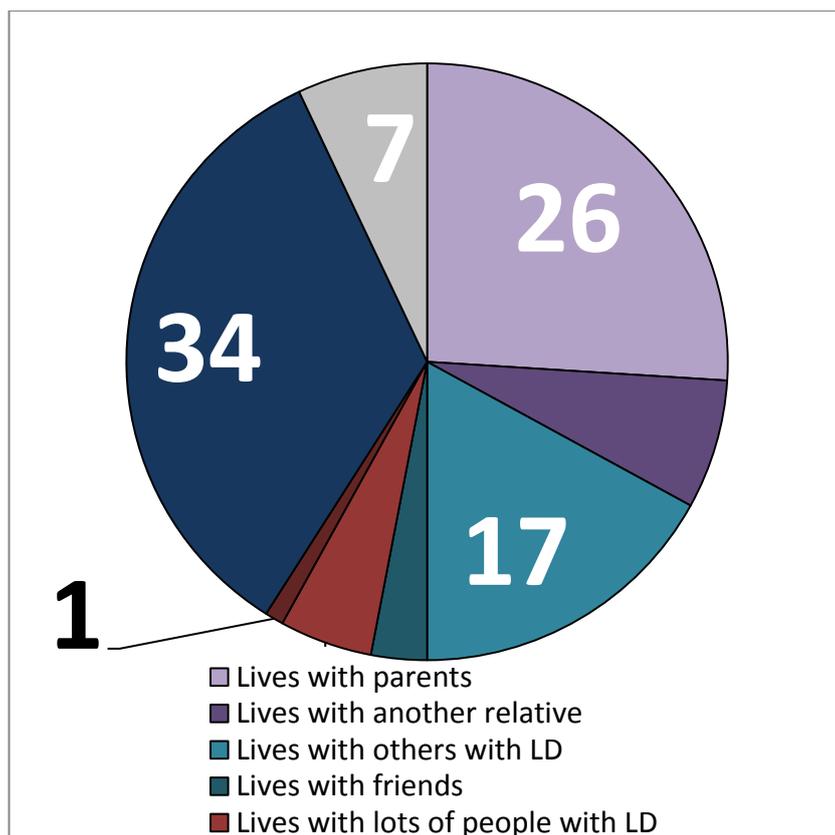
In order to gather more nuanced, embodied information on the learning disabled residents of GG&C, the NHS GG&C LD Database sample was again used – as explained in chapter 3 – to send 1000 questionnaires, of which 223 were returned, a response rate of 22.3%<sup>46</sup>. These respondents were residents from across the GG&C region, 43% of which were female and the majority male, with the youngest respondent being 19 and the oldest 88. A mix of locations, age groups and genders ensured that information collected represented a balanced view of those PWLD living within GG&C, allowing for data which represented a number of different situations. Of importance for this research were those residential scenarios in which PWLD found themselves, and Figure 17. indicates the living arrangements discussed by respondents.

Presented in this format, it can be seen that a majority of 34% of respondents do indeed live on their own, with 33% living with parents or another relatives; these numbers roughly correspond to the GG&C-wide information collated by SCLD (2015) which show 40.9% and 40% respectively.

While the mapping exercise above drew attention to those residential care spaces which more readily mirror the institutions of the past, this sample reveals only 24% of PWLD living with others

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<sup>46</sup> A response rate of nearly a quarter (as detailed in Chapter 3) should be regarded as a very decent return for such a cold-calling questionnaire survey (See Appendix 2).



**Figure. 17.** Showing the percentage of residential distribution of the research sample

with learning disabilities, an arrangement which can also include private tenancy agreements and small scale charitable homes. Although many PWLD are living on their own or with partners, this questionnaire information fails to encounter those embodied mundane spaces of the everyday in which care and support can be enacted in myriad ways. Although further informing what is known about PWLD in GG&C, the questionnaire data still leaves gaps in knowledge regarding residential decision-making, movement and belonging as experienced by PWLD.

Also of interest was the change in residential spaces across the life-course, giving more insight into how residential spaces for PWLD have transformed alongside cultural discourse and political rhetoric. Of 223 respondents, 14% had begun their residential experiences within long-stay hospital settings or lived in an institution of some

description<sup>47</sup> at some point. It would be expected that many respondents over the age of 40 may have spent time in an institution during their earlier years, but the sample of respondents here shows that the youngest person to experience such spaces was only 26 years of age. It is somewhat disconcerting to learn that someone of a similar age to myself would have spent many years within a hospitalised institutional setting, although, again, the ‘disembodied’ nature of the data – even of my questionnaire – does not lend itself well to explaining the ‘why’ of this situation.

Of the 14% who had lived within an institution, four respondents had found themselves in more than one hospital setting, suggesting perhaps that, as needs have changed through the life-course, so too has the residential hospital facility which is best suited to the individual. Many of the institutions discussed by respondents fall outwith both current and historical NHS boundaries for GG&C, so giving the impression that residential spaces for PWLD were based more on where could cater for their needs, physically and mentally, than where could be considered socially appropriate. Consequences for building networks with family and community are apparent, with displacement and unfamiliarity of surroundings flagging themselves as potential stumbling blocks to a sense of independence and non-learning disabled community integration. This is not to say that these residential spaces could not feel homely or hold sentimental value for those who spent time there, with hints of personal connection coming through the questionnaire data in the colloquialisation of hospital names and in the addition of carers’ script on the questionnaire itself, offering further clarification on the ‘correct’ name of the hospital. One respondent notes that he had lived in Merchiston<sup>48</sup> for 20 plus years.

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<sup>47</sup> Meaning group homes and residential nursing homes for the elderly.

<sup>48</sup> Officially named Broadfield Hospital, Merchiston Unit, and situated in Johnstone Paisley, this hospital opened in 1925 and catered for mentally deficient men. Redevelopment in 1958 and 1979 increased provision in the hospital before it was

It is difficult to imagine that in this time he built up no rapport with the people, spaces and places of the hospital, despite its apparent unsuitability as a long-term living option. These small moments of anecdotal musings scribbled around the questionnaire, begin to emphasise that moving residential setting may never have been within the means of their choosing, but nonetheless settings where they ended up may have become 'home' in all its familiar comforts for some PWLD.

Moreover, insistence on the closure of all long-stay facilities through policy recommendations may in fact have impelled yet another forced shift from one residential setting to another, failing to take into account the experiences of the people for whom this space just may have constituted home. For others, a forcible shift in residential experiences was not due to the closure of institutional spaces, but rather a change in circumstances:

Following the death of my parents 9 ½ years ago I moved in with my  
sister and her family

I live with my stepdad Bernard since my mum passed away

I live with my uncle as my mum died when I was 11

(Anonymous Questionnaire Annotations, 2015)

Annotations and further explanations added throughout many of the returned questionnaires begin to make clear the turbulent residential history of many PWLD, mentioning a variety of semi-institutional experiences from long term residency in a convent and stays in Salvation Army homes for the homeless, to group homes in which "sometimes they [other residents] shout a lot. I don't like when they

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eventually closed between 2007-2008, most recently the land was sold to David Wilson Homes for property development  
(<http://www.archives.gla.ac.uk/gghb/collects/ac44.html>)

shout". From my questionnaire evidence there has not been a simple and smooth shift from the asylum, to the institutional hospital, to one's own home, and nor can experiences be easily categorised and catalogued better to fit the arrival of an imagined residential enlightenment. Instead, what the questionnaires bring to the fore is the everyday messiness through which PWLD live their lives and experience their residential settings. This sample hints at the individuality of residential experience for PWLD as they align, perhaps new, residential possibilities with the everyday realities of care, experiences of decision-making, feelings of belonging and freedom (or not) of movement. Such matters will form the heart of the qualitative materials to follow in the next three empirical chapters.

#### Mapping residencies

Throughout this chapter the historical spatial, cultural and political practices relating to the residential whereabouts of PWLD have been variously unpicked, challenging how PWLD have come to be known and represented through their access to residential spaces. The socio-cultural happenings which removed the 'idiot' body from the community and into large-scale institutions has clearly been mapped out across the Scottish landscape, framing the stories to be told in Chapters 5, 6 and 7. Residential space for PWLD has been rethought time and again as the rights and abilities of those labelled as learning disabled have, albeit slowly and continuously still, been recognised and accounted for by those people who make residential decisions on their behalf. This is highlighted throughout the chapter in discussions of the role of key Scottish policies which have, and continue to, shape the lives of PWLD as they moved out of large institutional spaces and back 'into the community'. In Scotland SAY? began a real shift in the impact of policy, recognising, perhaps for the first time, the complexity of providing decision-making opportunities and choice which could truly begin the shift away from long-stay institutionalised

settings, as idealistic as many of the recommendations may here seem in hindsight. Moving forward, *TKTL* further solidified the need for suitable home spaces which reflect the individuality of learning disability. Although also fairly idealistic, the aim of this policy is not so much to oust 'the institution', but to address the raft of problems surrounding the finding of suitable home spaces which allow those with learning disabilities to live an independent life, while still having their needs accounted for and managed.

Recognising these political frameworks as a springboard for residential change, the chapter has followed PWLD on those first steps out of large institutions (outlined in Table 2.), mapping out the GG&C study sample, making clear the variety of residential experiences relevant to PWLD contemporarily. Throughout the life-course of those within this study, it is clear that there are a number of 'home' experiences and residential landscapes through which PWLD move and are moved. Yet, it is the in-depth everyday knowledge and undertaking of these residential realities which now requires further investigation, and so Chapter 5 begins qualitatively to illuminate the experiences of 'home' for PWLD. In particular, it serves to make clear those acts of residential, and indeed every-day, decision-making, which are not given voice within the pages of policy or reflected in the mapping undertaken within this chapter.

## Chapter 5

### The art of making decisions

The act of decision-making is a skill, which for many PWLD, is missing or undervalued. It cannot be assumed that adults with learning disability are automatically afforded decision-making capacity upon reaching the age of maturity, as those without learning disabilities may expect. Moving away from a review of the policy and literature, this chapter hence takes a qualitative approach in order to delve further into the processes of choosing. It deploys case study evidence in order to highlight how support, and control over that support, shapes how those with learning disabilities approach those occasions when they are able to enact change in their lives, if at all. The research undertaken and reported here draws on positive experiences of decision-making and, conversely, on those who have experienced barriers to choosing, so advancing what is known about how and why decisions are made and at what scale. Finally, the chapter draws to a close by reflecting on how these decision-making practices are enacted in decisions regarding home.

#### ***Support and control; trust and worry***

Essential for those with learning disabilities, is the support available to aid in the decision-making process when and if needed. While some PWLD are able to make and action decisions autonomously, for others these processes are shared and influenced, albeit to different extents, by those who provide their care and support. Arguably, this is not an experience which is far removed from those without a learning disability and, indeed, care and support relationships exist between all kinds of individuals, all of 'us' included, in various emotional and financial roles. What is different here is that many caring and supportive roles are not carried out solely by parents or relatives, but by external agencies. This difference opens new channels of

institutional influence in the private sphere of the home and throughout everyday lives which may influence both opportunities for decision-making and decision-making itself. These care relationships with key workers, support workers, carers, parents and guardians<sup>49</sup> are therefore extremely important when considering how and when PWLD make decisions about their lives and, ultimately, for the purposes of this research, how this impacts on where people live.

As such, it is significant to reflect on how trust within these care relationships is created and maintained in order to support the types of decisions which PWLD may want to make. Trust was a theme which continued to arise during interviews with parents and relatives, who worked alongside non-familial carers to help with certain aspects of their learning disabled relative's lives. Trust, as Giddens (1991:96) sees it, involves the "opening out of the individual to the other" in the hope that the other is committed to upholding ones' best interests. As such, trust is inherently risky (Parr and Davidson, 2008); a co-constitutive relationship which is the product of "participation and mutual communication" (Solomon, 2000:235). The care relationship begins with professional trust (Mechanic and Meyer 2000: 235); in faith that good care will be administered<sup>50</sup>. Care relationships for some PWLD, and their families, involve long term interactions with paid caring others, and so a highly subjective feeling of trust is crucial. Entangled within this notion of trust are feelings of worry. This worry derives from concerns about their loved ones' safety and, more so, the ability of outside agencies to provide the same level of care, given that neither parents nor those PWLD had any influence over who was brought in to provide this care. The 'letting go' of full parental control

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<sup>49</sup> For consistency throughout, the term 'carer' will be used to denote key workers, support workers and carers who represent care agencies.

<sup>50</sup> For more in-depth commentary on 'trust' and 'health,' see Brownlie *et al* (2008).

instigated for many PWLD the first steps towards a more independent life in which the act of decision-making could be explored and tested.

Trust in their carer allowed many respondents to feel more confident in their convictions during interviews. As the researcher found, differences in behaviour, including greater confidence and willingness to answer questions, were evident when the bond between PWLD and their carer was strong. Having interviewed Scott (20) on three occasions, with two different carers, the difference in his ability to assert himself when supported by Dawn was evident. Throughout interviews Scott would look to Dawn for support and guidance; she would prompt him to remember a story and together they would reminisce about hard times and fun times, inviting the researcher into the conversation. In doing so, a supportive and genuinely caring environment was created, in which Scott was supported to be in control of what was said and how much detail was added. These trusting relationships also allow many respondents to experience new things outwith the home setting, in some instances being furthered by charity-run befriender schemes, whereby volunteers spend evenings with learning disabled individuals doing tasks that they might enjoy such as going to the cinema. Through regular contact with volunteers away from the familiar surroundings of home, respondents such as Nicola and Rebecca were seen to expand their 'social knowledge' and so learn skills which developed their abilities to express themselves.

In partial opposition to this scenario, Darren (42) spoke of his preference for some carers over others and his willingness to discuss some issues with only a select few of the carers assigned to him. In certain care relationships, trust is hence not established and in this case compromised how Darren approached discussions and subjects important to him, further emphasising the role of trust in establishing control and decision-making for PWLD within the support setting.

Carers must ideally not only develop trust with the PWLD who they support, but also create an environment where the PWLD is supported to be self-aware; to understand that they can make decisions about their lives and that these decisions will be acted upon. Throughout the research process, this issue became apparent in different personal interactions between respondents and their carers. For Paul (62), moving into a house of his own was a huge step and a decision that was made largely on his behalf by the charity who oversee his care. In order for the move to be successful, Paul required 24-hour care, and so his relationship with his care-givers was, and is, of utmost importance. Through a trust-building process of learning about who Paul is *beyond* his care needs, Paul and his carer were able to discover a common ground on which to build a life filled with things significant to him. Supported to discuss his preferences (in themselves small-scale decisions), Paul was able to express a love of paddle steamers, now evident in the pictures and paintings which hang around his home and collected on various trips taken with his care team. By prioritising his decisions on how he spends his free time, Paul's carers have provided a space in which he is both fully supported but maintains a level of control.

Respect for PWLD's right to control their lives goes beyond a recognition of hobbies and interests, and also includes support of smaller-scale idiosyncrasies which may perhaps be considered 'non-normal', but ultimately for the people concerned bring a sense of happiness, calmness or control. The reality for Eilidh (29) is that everyday interactions can be a challenge, and so she finds solace in copying down song lyrics from her favourite albums. Pamela (51), on the other hand, chooses to spend much of her free time building Lego towers. These small acts may not be considered productive, if this is the narrow view by which time 'well spent' can be described; but,

through attentive support which recognises the right to choose, both Eilidh and Pamela have become more positively self-aware.

These small-scale decision-making opportunities have allowed many respondents to feel comfortable 'in their own skin'; to know that their actions are considered wholly ordinary in the context of their lives, something not to be eradicated, but encouraged. Decisions such as these are not always respected, however:

*I was in Tesco's and there was this young lad and there was a female carer and a young carer, the young lad [with learning disabilities] wanted to pick a DVD and the carer said to him, you know, 'that's too young for you' and goes on, 'that's too young for you' and I said 'what's that all about?' I said, 'if he wants that, then why not give him it? You're going to get him all agitated. She's going to get him a DVD he doesn't blinking want to watch anyway'. Why not let him get what he wants? ... my lad still watches Thomas the Tank and all that at his age!*

*(Robert's, father)*

In this particular scenario, Robert's father expresses his frustration at what he perceives as a lack of appropriate support. It is clear here that the carer is looking to avoid infantilising her service user, but in doing so she has removed his decision-making capacity. Moreover, experiences such as this run the risk of perpetuating negative associations for PWLD with the act of decision-making itself, which may in turn hold consequences for choosing in future. It is essential that support continues to find a balance around the difficult line between prompting PWLD to try new things and encouraging them to make decisions and opinions known.

### *Feeling 'in control'*

In order to bring choice and control into the support setting, charities such as The Richmond Fellowship<sup>51</sup> allow service users to opt in and out of more support as required. Kim (47) explains that she has “people to help out if I’ve got any problems”. Although she has a regular carer, in the form of a key worker, Kim feels able to request help in certain areas, such as banking, only when it is needed. This takes into account her ability to do many tasks alone, but leaves her the option to ask for extra help when she feels the need for it. Despite being supported to live alone, Kim maintains a feeling of independence through a decision-making process which builds her self-confidence and provides a network where she can have confidence in her own wants, needs and opinions.

It is important to consider, then, what PWLD are making decisions about and how these opportunities impact on their feeling of control. Maria (64) describes how her support has been changed to accommodate her needs, freeing up her “Sunday morning because it’s a mad rush to get ready”. As Maria settled into an independent life at home after the death of her parents, she no longer felt the need to have carers call on a Sunday morning when she preferred to relax, and flexibility in her support system allowed such positive changes to take place. Choice and control over support is also enacted through selecting which clubs to attend, when and where:

**Mother:** *Enable*<sup>52</sup> group has a drama, a class, an evening in the town hall on a Monday and a Thursday, but [Eilidh] doesn’t want to go.

**E:** No.

**V:** Did you try it and didn’t like it?

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<sup>51</sup> The Richmond Fellowship Scotland is a charity who supports over 2800 people across Scotland with a broad range of needs to live as independently as possible in their own homes and communities ([https://www.trfs.org.uk/who\\_we\\_are](https://www.trfs.org.uk/who_we_are)).

<sup>52</sup> Enable Scotland is a charity who campaign against learning disabled discrimination and provide person-centred services to allow PWLD to actively explore their communities (<http://www.enable.org.uk/aboutus/Pages/default.aspx>).

*E: Years ago.*

**Mother:** *She did go back to see if it was any different and she might like to go, but she didn't want to go.  
(Eilidh and her mother)*

It was clear that Eilidh's mother would like her to try to go back to the club due to parental worries about a lack of socialisation, but her mother's role in supporting Eilidh to express her thoughts and feelings allowed Eilidh the confidence and self-awareness simply to say 'no' with the knowledge that she would not be judged for saying so. Control such as this, on a small scale, can be extremely empowering for some PWLD; "He's got to the stage where you've got your coffee, tea, Horlicks all lined up and he'll go over and pick what one he wants" (Robert's father). Robert (34) is unable to communicate verbally, but his family have worked closely with him to begin building opportunities in which he has the support to make choices. The notion of free choice could easily be critiqued here, but such reductive critique fails to recognise the significance of learning to choose. Simply having a choice is not enough, if one is not versed in the act of choosing, something which many PWLD are not supported to do on regular occasions.

Where support and control are not correctly balanced, respondents feel disconnected, unsupported and inconvenienced by the care received:

*They all come and then see if I've done anything and last week I told father [the priest] that I can't deal with it. After dinner they walked right into my room and I said 'Margaret!', and she said 'what?', and I said 'get out of my room and don't come in my room again'; and then the father came and said 'what happened?' and then he put them out.*

*(Lynne, 68)*

As evidenced by the above interview extract, Lynne continues to feel a lack of control over her life since being moved to a residential care home against her will. Given Lynne's age and learning disabilities it was decided (by whom Lynne cannot tell me) that she could no longer take care of herself and would greatly benefit from moving to the fully catered home in which she currently resides. While this may have been the best option for her physical wellbeing, Lynne continues to feel frustration at her lack of input into this decision. Even during the interview process itself, many members of staff entered Lynne's room without permission, putting things away, taking laundry and searching for items within her drawers and cupboards. Although no malice was intended, quite the opposite in fact, Lynne's lack of ability to decide who entered her room, and when, engendered bitterness towards those who provided her care. Lynne's experiences highlight crucial links between decision-making experiences and residential location.

Control and decision-making within support networks can therefore be seen to impact on how independent PWLD feel in their everyday interactions. It can easily be assumed that independence equates to 'doing things alone', but it is clear that independence for PWLD is a complex set of interactions which involve support from those around them to achieve self-confidence in the worth of their decision-making capabilities; a shared making of independence (Hall and Wilton, 2016). Arguably, this is not as far removed from the non-disabled experience as may first be assumed. Finding support outside of the family can also be an empowering experience, and Aimee (29) finds confidence in knowing that she has a little extra support where needed, saying "Joan does the shopping, the big shop with me and I do the small shops myself". In connection with her local day centre, Aimee has learned to carry out small, seemingly mundane tasks alone, but with the knowledge that, when she struggles, someone is nearby to offer help and guidance. This type of support is becoming

increasingly rare, although highly sought after, as funding cuts impact on the ability of such services to remain available. Naturally, the knock on effects for feelings of independence, support and control are most tangibly felt by those with LD who currently strive for an alternatively normal life.

### *Independence and support*

Chapter 3 outlined the new political move towards personalised social and health care, a move which sought to give PWLD more control over their support. The experiences which follow begin to showcase how these policies impact PWLD in their daily lives. Decision-making and independence can become further polarised when caring support networks are your nearest and dearest; “At the end of the day he is mine and I know then, whatever he does, he does it for me” (Barbara). In choosing to be supported by her husband, Barbara feels more able to make decisions about her support, to speak openly about her needs and create goals for the future as part of a team, as opposed to within a carer/cared-for relationship. Again, these decisions are hindered by governmental changes in how support for independent living *should* be decided upon and mobilised, again picking up on the role of self-directed support in allowing more, or indeed less, independence for learning disabled lives (a subject discussed in more depth at a later stage).

Where support cannot be controlled, those interviewed express a fear for the future and their ability to maintain independent lives. Carol’s mother discusses the impact of support breakdown in the transitional stage between school and the resulting insecurities over the next phase of Carol’s (29) life:

*She went to the resource centre [in the local area] but she wasn’t happy there, she wasn’t comfortable.*

*She was trying to escape and I just wasn't happy either, everyone was busy. She went straight there from school at 19 to a resource centre and it was overwhelming for her.*

*(Carol's mother)*

Provided with a lack of support options, Carol attended a resource centre, but it is clear that within this space her social needs were not being prioritised. Rather, it was a place to 'hold' Carol 'securely' as opposed to a place in which she could further develop her self-esteem and confidence. Without strong vocal communication skills, Carol displayed unhappiness and discomfort by making regular attempts to leave. Although discussed as attempts at 'escape', these occurrences could instead be understood as Carol's expression of free will, as a non-verbal communication of her opinion with regards to her support. Recognised as such by her familial support networks, Carol was able to build a care package with Cosgrove Care<sup>53</sup> which recognised her aspirations, while respecting her right to spend time alone when she required it.

Support and control can become more problematic when those with learning disabilities feel that their care is based around an all or nothing, one size fits all attitude; as Darren states "You don't have any control at all. Take it or leave it. That's all it is now. Take it or leave it. If you don't like it, tough. That's what it is now". In Darren's experience, choosing whether to have care or not is not the issue, but rather he feels restricted within his support package to make decisions and changes which best suit his requirements. This lack of input has led to resentment towards not only his carers, but also at the support provided in general. Making an indirect comment on the privatisation

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<sup>53</sup> Cosgrove is a charity who provide a range of services for children and adults who have additional support needs, a diagnosis of a learning disability or an autistic spectrum disorder([www.cosgrovecare.org.uk/our-teams/](http://www.cosgrovecare.org.uk/our-teams/))

and the contracting out of services, Darren explains, “well you see, a lot of the good ones left because they [the care company] paid them off and they got in...just ordinary people”.

An absence of trust in the abilities and motivations of those sent to care for him creates an environment in which Darren feels that he is unimportant in decision-making about his own support. Perhaps notable here, in demonstrating these emotions, is the use of the word ‘ordinary’ when describing carers. This highlights an underlying mistrust of carer training evident throughout interviews with Darren, and it is clear that his lack of decision-making opportunities in this area impact greatly on how he feels mentally. Alongside his learning disabilities, he also battles depression, and finds that his carers are not as attuned to his needs as they could be. Recognising his depression himself is something on which Darren is working, his dip in confidence with regards to his care team nonetheless causes him further concern over identifying when he is becoming depressive. Throughout interviews, it is clear that this is a main priority for Darren, but he does not feel that this is the main priority of his carers.

As such, it is important for decision-making and control not merely to have the choice of a care package, but also to have choice and control within these official care networks. Carers occupy a problematic in-between whereby they must provide an acceptable level of care for mental and physical wellbeing (bearing in mind that care agencies are businesses with impact and output targets), while also creating an environment for development of self-esteem, confidence and decision-making abilities. Similarly, this care must also recognise and respect the autonomy of PWLD, in particular with regards to their right to make decisions which may be wrong; tying in yet again with Wolpert’s (1980) claims about the ‘dignity of risk’. Recent history has noted a proclivity for infantilising those with LD; it is evident that those

with learning disabilities should be allowed to fail, even in small ways, in order to further their decision-making experiences. The difficulty then comes in providing support where it is recognised that decision-making abilities in those with learning disabilities are not necessarily inherent and may need to be taught through trial and error without judgement. Where decision-making is not nurtured, resentment can build, but it must also be acknowledged that some PWLD may not choose to be supported, but may still need support. Conversely, trust and control within the support relationship can be seen to build confidence and self-esteem, which positively impacts on the ability of PWLD to make decisions about their lives and, ultimately, about their residential opportunities.

### ***Positive experiences of decision-making***

Moving beyond thinking through the decision-making opportunities within official care networks, many of those interviewed express positive feelings around decision-making on a number of issues of importance. These decisions varied in scale and impact but, nonetheless, illustrate the wider consequences for confidence, independence and overall happiness experienced by those with learning disability when choices are made by them. It is worthwhile noting that these experiences differ across those interviewed, and are *not* dependent upon level of learning disability as may initially be assumed, further adding weight to a 'nothing about us without us' approach to learning about and catering for learning disabled lives

Although within this research the voice of the learning disabled person themselves is prioritised, it is pertinent to acknowledge that much decision-making still originates from parental carers. This appears especially true when the PWLD has little to no communication skills. Understandably, many decisions made are done

so from a protectionist stand-point, where, with the best of intentions, many parental carers make choices which keep their loved ones safe but may not expand their social horizons. For Robert (34), his parents felt great concern at the thought of allowing him to attend Respite<sup>54</sup> care:

*V: How did you feel about [Respite] when it was first kind of [mentioned]?*

**Mother:** *Couldn't sleep.*

**Father:** *Terrified.*

*(Robert's parents)*

Emotionally, Robert's parents found it difficult to imagine passing his care over to others, having made decisions about Robert (34) together throughout his life:

*If you've got kids you'll know yourself you don't want them to leave yer and he used to lie at the front door [of the respite centre] no matter how many times you tried to put him into bed he'd go back waiting for us to come, and when I heard that! Oh!*

*(Robert's mother)*

Despite reservations and early difficulties, Robert's parents made the decision to persist to allow him the opportunity to socialise with others, expressing a need for him to learn while they are still around to help. By opening up his social worlds, Robert too has been called upon to make decisions regarding his life. Since they began to utilise respite services, Robert's parents have noticed positive changes in his behaviour, including the ways in which he expresses himself in order

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<sup>54</sup> Respite care encompasses care homes, home care services, day centres, and holidays which allow family carers to take some time for themselves for whatever reason. Respite can also be taken if the person being cared for needs hospital aftercare, would like to try living away from the family home, or would like to take a holiday. As such, respite comes in many forms and each PWLD and their families use it differently.

to make small-scale choices such as which DVD to watch and when. These may not be life-altering decisions, but these steps towards independent expression of desires can be clearly seen to have their roots in the more progressive decision-making of Robert's parents. Of import here, then, are the ways in which decision-making skills have been learned by Robert and supported by his family, growing positive attitudes to choice-making which may promote yet more independent decision-making in the future.

In some instances it is clear that decisions are made through negotiation between those with LD and their closest care-giver, but this does not negate the positive experiences that such interactions can deliver. Alongside his carers, Paul (62) was supported to choose the ways in which he would like his life to develop:

*Before, he was an independent traveller and he used to travel to Ayr every day, but he used to cost a lot of money through railway tickets etc. so we ended up, told him if he became, if he stopped going to Ayr every day, then we would help him and start taking him on holiday and that's what happened! Because he couldn't go on holiday and pay 60,70 pounds a month. And then he's got his shopping and everything else on top of that, and as soon as he stopped that, he got a house and that made him a wee bit more independent.*

*(Paul's carer)*

Paul was given a realistic either/or decision to make about his living arrangements which called for a consideration of his ambitions for the future. He enjoyed the journey to Ayr and spending time there but did not necessarily *need* to go, and therefore he was supported to choose an option which allowed him to have a home that he both wanted and needed, alongside holidays which he enjoyed. While this decision-making scenario was initiated in a top-down way by his carers, Paul was allowed to make the choice for himself while being supported to

understand the implications of each decision. It could be argued that, without prompting from his care team, Paul would not have been aware that such changes were available to him. So, while being completely capable of making this decision, he may never have envisaged these things for himself or known how to make them happen. By introducing him to realistic new ideas for his future, Paul's care team created a positive decision-making environment, one which has left him feeling more proud in his independence and resulted in him discovering new places where he is happy, comfortable and fulfilled. This is not to say that Paul no longer visits Ayr, but rather, that he now understands the implications of choosing to visit Ayr each day.

Decision-making abilities can lead to positive changes when PWLD are educated to understand their learning disabled body spaces. Having contracted Swine Flu, Jordan (24) lost the ability to walk and so undertook years of rehabilitation in order to learn to walk again. Moving forward from this, Jordan decided to attend personal training sessions at his local gym, together with his personal trainer, developing a programme which rebuilt his strength and stability. With regular visits to the gym, Jordan chose to make active changes for his health, explaining "I like to do my weights, go on the rowing machine and just keep my weight down". His decision to take control of his weight and learn more about his abilities permitted him to make informed decisions about his own health. Moreover, he is now able to set targets for himself and takes pleasure in hitting them. Learning to assert himself in this environment has driven Jordan forward to make other decisions about his life, such as getting a job and volunteering for the organisation through which he gets his care.

Prospects for positive decision-making can also be developed through attendance at different groups and clubs, where many PWLD find that

their social circles are widened. For Aimee, choosing to attend Dates-N-Mates<sup>55</sup> has made a tremendous difference to how she feels about socialising:

*A: They've got learning disabilities, a lot of them have, sometimes they've got a lot.*

*V: And does that make it easier to chat to them?*

*A: Uhuh, then they become your friends and that's a nice thing as well.*

*V: So have you met a lot of friends through doing that?*

*A: Yeh uhuh!*

*(Aimee)*

Knowing that those in attendance also have learning disabilities makes Aimee feel more confident about talking to others, positively impacting on her ability to express herself in a number of different social situations. Clubs such as these allow PWLD to meet like-minded individuals without the stigma of learning disability being an issue, so encouraging social decision-making within an environment of safety. PWLD can often express discomfort in liking or, indeed, not liking people that they encounter, and so experiences such as this one open up a space for honest, supported discussions regarding opinions of others, important in many areas of life. Hall (2004) notes that PWLD occupy a precarious positionality between inclusion and exclusion since they experience social exclusion on a daily basis, but hold limited capacity to gain access to spaces of inclusion (In Hall's example access to employment). Within this inclusion/exclusion binary, geographers, such as Antonsich (2010), have targeted 'belonging' as a much needed "conceptual escape" (Hall, 2013: 246). According to Hall (2013), this sense of belonging is sought within 'safe spaces', through everyday and uncommon practices, with known and unknown people, and in familiar and unfamiliar places. It is therefore crucial that PWLD are

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<sup>55</sup> Dates-n-mates is Scotland's national dating and friendship agency run by and for adults with learning disabilities (<http://dates-n-mates.co.uk>).

afforded the decision-making capacity to explore these spaces of belonging. In positioning herself in a socially comfortable space (Dates-N-Mates), Aimee blurs the distinction between inclusion/exclusion further still, by seeking out spaces in which she feels that she belongs. Inclusion, then, cannot ever simply be about access to the non-learning disabled mainstream, but also continued access to alternative learning disabled spaces in which PWLD can *choose* to find comfort and friendship; an increasingly difficult task as funding for such projects dwindles.

Positive experiences of decision-making need not only come from one particular event nor occur in one particular space, since for some with LD the act of decision-making can continue to present new and different opportunities:

*K: The travel, I go on buses and trains so I do.*

*V: So you do a lot of travelling?*

*K: I do.*

*V: And do you feel quite confident?*

*K: Yes I do, uhuh*

*(Kim, 47)*

Travelling freely on buses and trains allows Kim to make decisions about where she goes and when. Feeling unhindered in making these decisions builds her confidence and allows for new experiences in new places. Furthermore, her ability to travel has also allowed for her to be simultaneously close to college and to her mother, while still living an independent life alone, all things which are extremely important to Kim's vision of her life.

### *The impact of positive decision-making*

Positive associations with the act of decision-making can be experienced in myriad ways, but it is essential to understand that each

experience, large or small-scale, feeds into a sense of pride, accomplishment and overall happiness which those with learning disabilities feel. Some may still need help to recognise that options exist, while others will always need someone to act on their behalf in some capacity. It is necessary to note that how these decisions are reached, either on their own or in conjunction with others, does directly impact how independent PWLD feel, but not always negatively. Much like those without learning disabilities, support in making decisions important to the individual can encourage decision-making. Conversely, there are those who would rather make decisions alone. Recognising that those with learning disabilities are no different in this respect is key to ensuring that PWLD continue to reflect positively on the act of decision-making.

### ***Barriers to decision-making***

As illustrated previously, PWLD can and do have positive decision-making experiences, but all too often they also face barriers when making choices. These choices impact on the everyday, sometimes mundane, realities of living a normal existence as a person with learning disabilities. For the purposes of the current research, these barriers can be neatly packaged as ‘personal’, ‘social’ and ‘political’, reminiscent of the ‘barriers to doing’ and ‘barriers to being’ described by Thomas (1999) in Chapter 3. It is rare that they would ever be experienced in such a clearly demarcated fashion, rather, there are many ways that each of these sub-themes are linked and entwined for each learning disabled individual.

#### ***Personal barriers***

Some perceived barriers to decision-making are personal, internalised fears and anxieties which hold some PWLD back from experimenting with new activities, places or people. Grant (31) is fixated on the worry

that he would be unable to cook for himself should he choose to move out of his parent's home. Similarly, Scott (20) harbours insecurities based around perceived weaknesses in his own personality:

*That's why I don't want to keep hearing all the arguments [with his siblings], kind of want to not know it because my mum is saying to me I've got to keep calm, and Dawn [his carer] knows, if I'm upset, you've got to walk away and ignore it because you'll get yourself upset and you have to walk away. And that's why I'm doing it now, I don't want to get myself under pressure and to get, get myself un-understandable and in a state.*

*(Scott, 20)*

Scott struggles at times to control his temper and, while it causes him concern within his family unit, he also struggles to imagine how he would cope should he secure a part-time position. At the time of interview, Scott had been offered a part-time job at a local café, which he was keen to take. Since moving on from school, it had been important to him to get a job, something he thought of as the 'normal' thing to do. However, his decision to accept the job or not was greatly hindered by how he would impact upon his work environment if he could not manage his anger. This personal barrier, which Scott was attempting to overcome, nevertheless affected his decision-making even though opportunities had been presented to him.

Other personal barriers to decision-making include those health concerns which run alongside learning disabilities, such as depression, anxiety and addiction. These conditions (co-morbidities) not only impact on the options made available, but also on how decisions are considered and made. For Mike (29), personal circumstances greatly impress upon his mental health:

*All the time my emotions was terrible and Susan [his family friend and carer] dealt with all my emotions*

*and they used to pin me down all the time, but it was worse last year. What it was, my father died and the way I found my father [dead], and I couldn't get it out ma head.*

*(Mike, 29)*

After the death of his father and also his brother, Mike struggled to cope and lost touch with the things that he had planned for himself and his future: "I had long hair and that then, I wasn't taking care of myself and Susan noticed it, but I just kept hitting the bottle". Parallel to his grief and growing depression, Mike was also dealing with addiction to both drinking and gambling, seeking little in the way of help. These problems stand both outwith and enmeshed within his learning disability. Depression and addiction are experienced by those without learning disabilities<sup>56</sup>, but for Mike, having learning disabilities made it difficult for him fully to understand what he was experiencing as it was happening. Although not solely linked to his learning disability, it is fundamental to acknowledge the complexity of learning disabled lives and emotions, and to consider the impact which such co-morbidities can have on how decision-making is approached and carried out.

The spatiality of decision-making can also interfere with how some PWLD perceive the consequences of choosing. For Claire (51), visiting her family can be problematic because she does not know the area where they live well enough to feel comfortable:

*I'm alright if someone is with me on the bus but no myself because I get panicky because any situation can arise on a bus that you are not ... prepared for. And then when I get off the bus I get a wee bit confused by the area I've to go about you know?*

*(Claire 51)*

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<sup>56</sup> See Fisher and Harrison (2012), Taggart *et al* (2008) and Jahoda *et al* (2006)

Claire's decisions are entirely based around her fear of the unknown and the potential dangers that could lurk in spaces with which she is unfamiliar. This barrier to decision-making is entirely personal, in that it is not based on previous negative experiences in similar spaces and situations. Nevertheless, Claire's ability to make decisions about her life, hobbies, home and aspirations are ultimately dictated by anxieties which she herself cannot fathom. In order to understand how decisions are made, or not made, by PWLD, it is vital to know more about the real or perceived spatialities of decision-making – at root the chief work being undertaken by this chapter.

### *Social barriers*

Other barriers to decision-making are socially derived (see discussions around the social model of disability in Chapter 3) and arise through spaces and discourses which are potentially disruptive to the process of choosing for PWLD. William's father discusses the opportunities available for his profoundly disabled son:

*Another thing that is a sore point is that they can't go and get changed, I said that before. So it might be a great thing if they looked into that and made sure that they had enough changing places<sup>57</sup> for disabled people, and it's not just adults in a wheelchair that need to get changed.*

*(William father)*

Although William's father tried to create opportunities for his son to explore different social environments, he found that there were increasingly fewer places which recognised the severity of William's (27) condition. Most places which provided services for those in

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<sup>57</sup> Changing Places Toilets are highlighted in TKTL as a key agenda to be pushed forward. Started by PAMIS (a charity who work to support people with profound and multiple learning disabilities and their families, <http://pamis.org.uk/>), the Changing Places campaign is now a UK-wide consortium who work with the Scottish, English, Welsh and Northern Irish Governments to provide easy access to safe and dignified changing places for people with Profound learning disabilities.

wheelchairs did not cater for adults who required to change pads. As William Jr grew, it became more difficult to use baby changing facilities, many of which were only provided in the female toilets, and so there was a gradual reduction in the number of family outings. Social barriers such as this severely affect decision-making capacity by PWLD and their primary carers by limiting the routes available to them. Simply put, if there are no options from which to choose, there can be no decision-making, limiting not just “barriers to doing” but critically, “barriers to being” (Thomas, 1999:46).

Mae (50) has experienced similar difficulties in attempting independently to navigate her daily commute as someone who has both a sight issue and a learning disability which affects her comprehension:

*All the buses and all the trains are the same. When a bus comes towards me, it actually has to be right in front of me before I can see where it is going and nine times out of ten it has run past me, and the trains are the same. See, if I am going to Lenzie, there could be two trains in and I don't know which is going where till somebody tells me.*

*(Mae, 50)*

Although Mae is confident in making decisions about her daily activities, the reality is that she is making her way through a social environment which continues further to limit her abilities. Where independent travel is liberating for some PWLD, others find it debilitating and frustrating.

It is not merely societal structures which can prove taxing to decision-making opportunities, but also discourses which surround learning disabilities. Grant discusses his experience of being listened to when out and about:

**G:** *Speaking up.*

**Mother:** *Oh you've got to practise speaking up.*

**V:** *So sometimes people don't listen to you because they maybe don't understand what you are saying?*

**G:** *Mhmm.*

**V:** *Ok, that makes sense. So you think that you have to practise speaking up?*

**G:** *Yeh.*

**V:** *And you think that would make it better?*

**G:** *Yes.*

*(Grant, 29)*

Grant has Down's Syndrome and feels that his (sometimes) difficult-to-understand speech can hold him back when interacting with members of the public. It is telling that Grant feels that the onus is on him to make himself more understandable, even though his negative experiences are drawn from instances when others would not make time properly to hear him. This situation may, in part, be because people are afraid of appearing rude by having to ask him to repeat himself. Whatever the reason, the outcome is that Grant can feel uncomfortable about speaking to others, so affecting his capacity to make snap decisions when out and about.

#### *Political barriers*

Decision-making is further impeded by changes at the political level which, as already intimated in Chapter 3, continue to alter how services are delivered and experienced by PWLD. Perhaps the biggest shift in political discourse with regards to learning disabled decision-making in Scotland is the personalisation agenda evident throughout TKTL (2012). Seeking to address calls by many learning disabled people, carers and advocacy groups for more control over how care and support is managed and delivered, this personalisation agenda has made attempts at prioritising the care needs of the individual through the promotion of autonomy and choice. While this move may work for many PWLD, the experiences shared within this research cast

a less positive light on the realities of such changes. A theme touched on by many respondents was the UK-wide introduction of the Personal Independence Payment (brought in to replace the Disability Living Allowance by the Welfare Reform Act 2012), this shift focuses on tighter eligibility criteria, more punitive sanctions and a continuous process of reassessment throughout the life-course. For those carers of the most profoundly learning disabled respondents, this payment reform added yet more burden and, by combining it with self-directed support payment, many felt “you’d spent your life sitting here writing out, keeping checks on everything” (Robert’s father). For William (27), the changes impacted on the number of hours that he was able to have full-time carers for his son, leaving him to juggle between several care agencies and day centre facilities. As opposed to increasing decision-making abilities, these changes have, for some, left gaps in their care provision which require non-paid carers (e.g. parents and relatives) to step in, so limiting choice in many ways.

Others with less severe learning disability have also witnessed negative changes in their care options. Many of those interviewed rely heavily on the social interaction of attending day centres which are now in decline. These closures are multifaceted in their impact (as discussed in detail by Hall, 2004; 2005; 2007; 2011), arising as a result of the personalisation agenda and related budget cuts discussed previously, but also shaped by arguably misguided ‘social inclusion’ attitudes which cling to the ideal that having PWLD present in non-learning disabled spaces equates to societal integration on all levels (Hall, 2004). This is the gold standard to be reached, against which collective learning disabled spaces are seen as inferior. Additionally, there exists an ‘institutional hangover’ whereby these day-centre spaces are considered akin to institutionalised, set-apart, spaces which characterised historical accounts of learning disabled care (Hall, 2011; Power, 2013). The closure of many of these centres has left

those interviewed feeling undervalued in decision-making processes which impact on their lives. Jamie was asked about his experience of moving to a new day centre with the impending closure of his normal facility:

*J: We went down to see what it was like.*

*V: And did you like it?*

*J: Yes.*

*V: Good. What would happen if you didn't like it?*

*J: I would just stay in the house. They said if I don't take the budget money I won't get any service and I'll just stay in the house.*

*V: So how would you feel about that?*

*J: No. I get bored.*

*(Jamie, 52)*

Alterations in how care is managed and delivered has thus impacted on opportunities for decision-making and clearly, from Jamie's experience, indicates a disconnect between policy creation and the lived experience.

It was presumably not the intention of the personalisation agenda to isolate those with learning disabilities from the things that they enjoy, but this development further supports growing concerns that the marketisation of care services results in the reduction of quality and availability of services received (Power, Bartlett and Hall, 2016). The restructuring of state support for learning disabilities – including in (relatively expensive) collective learning disabled spaces – has left behind a 'shadow state' in which the private (voluntary) sector must fill the gap (Wolch, 1989). Darren and Maria (64) both express concern over the turnover of carers as they seek better wages at different care services, and, understandably, they are worried about the quality of care they are receiving. The changes implemented are not uniform across council boundaries or care services, creating an uneven landscape for decision-making opportunities for PWLD regarding their care.

Overall, barriers to decision-making exist in various forms and for different reasons, but it is apparent that treating those with learning disabilities as a homogeneous group results in unequal opportunities with regards to how choices are presented and decisions made. As such, it is imperative to consider learning disabled experiences of choice and decision-making as an entanglement of ‘personal’, ‘social’ and ‘political’ barriers which should not be considered in isolation, especially with reference to the political level. Without understanding how and why decisions are made, or not made, for a variety of learning disabled people, decision-making opportunities will continue to reduce. Moreover, and most critically, PWLD’s ability to recognise and make decisions about their lives will also suffer.

### ***Decision-making and home***

Chances for choice and decision-making may present themselves in different ways, through small-scale preferences, such as what to watch on TV, to larger-scale decisions with regards to services. Of importance within a post-institutional residential environment are the ways in which decisions about ‘home’ arise, are considered and, eventually, acted upon or not. It is vital to understand more about the role of PWLD in active residential decision-making, why PWLD choose to move home, or not, and how these decisions are influenced by those around them. Moreover, knowledge regarding how PWLD feel after having made decisions about their home situations can tell us more about housing needs for PWLD in the future.

### ***Choosing to move***

In asking why PWLD decide to move, it was obvious, as perhaps expected, that those with learning disabilities move home for similar reasons to those without learning disabilities. Entangled within these

decisions for many was the chance of gaining more independence. Having watched non-learning disabled siblings move out of the family home, many respondents sought this form of independence and responsibility themselves, albeit, for most, with some form of support agency involvement. As Wilma explains, she had watched her sister move out and friends in her peer group successfully move into their own homes, and so began to question her own feelings regarding home spaces:

*See when you've actually, you know, lived here since you were about two or three years old it gets a bit boring. After, you know, five or ten years, it gets a bit boring and you just go [blows air out of cheeks] 'I feel like getting a house of my own now'. I just see the same folk over and over again.*

*(Wilma, 23 )*

Although Wilma also speaks positively about her current living situation in her grandparents' house, it is clear that she feels constrained. As opposed to feeling safe and supported, she feels that her peers with learning disabilities are moving forward without her. So, seeking the opportunity to try new things, Wilma has pushed to find a new home which better suits her ambition for a more independent life, as she views it, away from the family home.

For others, the impetus to move home comes not from a wish to move forward to a brighter future, but rather to move away from a constricting and dangerous past. Mike's (29) experience of living in a particularly down-trodden area of Glasgow highlights how decision-making regarding home can impact on mental and physical well-being:

*That's where I was, that was bad. I was in a bottom flat, people were throwing stones and smashing it up and all that, some lassie got her car smashed up. I was up [at the centre] then and she came up and said*

*'you'll need to come back up the road they're going off their nut'. And they were stopping the trains and everything.*

*(Mike, 29)*

Living in this wider local environment was detrimental to Mike's hopes for the future and played into his negative mind-set at the time. The decision to move home sparked by his carer, and through the support that he received to do so, coincided with a happier and more positive outlook for his future. Crucially, it also resulted in renewed faith in his ability to change those things about his habits and life style with which he was unhappy. As noted in Chapter 4, those with learning disabilities tend to be housed in more deprived areas, which can negatively impress upon a person who is potentially vulnerable. The vulnerabilities may not be a direct result of being an learning disabled person, but nonetheless can exacerbate certain co-morbidities such as depression or anxiety. What Mike's experience neatly showcases is the empowering nature of decision-making regarding home, which can evidently greatly affect how those with learning disabilities feel about their lives and their opportunities for the future.

As with Mike (29), Barbara's experience of her immediate neighbourhood, combined with a lack of decision-making prospects, had consequences for how she feels about her accommodation. When asked if she liked her home, Barbara explains:

*The hills on my hips<sup>58</sup>. I love my house, don't get me wrong I do, but it's the hills that means I have got to get taxis every day. You know what I mean? And it costs you a good bit of money.*

*(Barbara)*

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<sup>58</sup> Aside Barbara's learning disability, she also has mobility problems due to her need of a hip replacement, for which she is currently on an NHS waiting list.

While Barbara loves her immediate home environment, changes to her benefits have interrupted her interactions within the surrounding neighbourhood. Having had her mobility car removed and her benefits cut, due to changes in what she is allowed to claim, her home has become somewhere that she cannot easily leave, cutting her off from many places within the community which she would usually visit, so influencing her feelings of independence. Her home has suddenly become not a haven but a trap, in part precisely because of the physical location requiring mobility up hills – hence ‘the hills on my hips’ is a telling expression of not just physical geography, but its intersection with fiscal and service geographies. Additionally, Barbara’s decision-making regarding where she lives is also removed, since her situation does not warrant a move to a more appropriate home under social housing rules and regulations.

The cumulative effects of loss of mobility, loss of independence and loss of decision-making privileges has disempowered both Barbara (48) and her husband, putting further strain on them financially and mentally. As such, it is key to provide suitable homes for those with learning disabilities which are not only residentially appropriate (e.g. in the physical layout of the property), but which also recognise wider social and environmental needs of both the individual – including physical mobility needs – and their extended family. Thus, allowing those with learning disabilities to make decisions about their residential locations, while also providing support to consider these wider issues of concern, can greatly improve wellbeing. This is not to suggest that those with learning disabilities should automatically be able to access housing of their desire without regard for cost or feasibility, but throughout the interview process respondents expressed confusion over why they could not access more suitable housing. This issue draws attention to detachment between those governmental agencies that make residential decisions for PWLD and

the people with learning disabilities themselves. Lack of appropriate communication between all parties concerned can further impinge on decision-making confidence, increasing frustration and the sense of being undervalued by non-learning disabled specific organisations. While advocacy groups<sup>59</sup> do exist to tackle inequalities for PWLD, situations such as these should only require mutual respect and understanding of the need for alternative communication practices, so including PWLD within discussions regarding their residential situations.

Notable throughout the research were those respondents who have enjoyed no decision-making input over their move out of one home space and into another. These respondents tend to have more severe learning disabilities, which has hampered their verbal communication. Colin discusses his experience of moving out of his parental home:

*V: And how did you decide to live here?*

*C: My mum and dad did it for me.*

*V: Your mum and dad did it, and did they choose [this group home] for you?*

*C: Yeh.*

*(Colin, 55)*

Colin moved from his parent's home into a residential group home for those with learning disabilities when his parents passed away. Having chosen this home beforehand, they made provision for his longer term well-being by ensuring that he would be safe and cared for. Although this decision was made with the best of intentions, Colin recalls being scared and confused by this change in residential setting, for which he was unprepared and about which he was not consulted. As expected, there are many reasons why PWLD choose to move

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<sup>59</sup> Such as, Learning Disability Alliance Scotland (<http://www.ldascotland.org/>), Turning Point Scotland (<http://www.turningpointscotland.com>), Capability Scotland (<http://www.capability-scotland.org.uk/>), and Partners in Advocacy (<http://www.partnersinadvocacy.org.uk/>), to name but a few.

house. What is apparent are the differences in what people feel about these residential moves based on how informed and involved they are within the decision-making process; an issue discussed further overleaf in Box 1. Those who are least happy with their residential situations are those who feel less connected to the process of choosing where to live and when to move.



Moreover, Blackwood Court offered possibilities for decision-making, indicated by the various dashed lines flowing out from his home which represent Lawrence's identified networks of importance. Lochy Park is highlighted as a space where he can take "wee walks" when he wishes and at his own pace, very important given his difficulties with walking. Within 'normal' urban spaces, he can, at times, feel rushed, the park allowing him time to amble, slowing down his need to make fast-paced decisions which can be difficult for him to do. Similarly, he enjoys going to Balgray Cemetery where the pace of happenings is a little slower and he can take time to remember his grandmother with whom he lived for many years. Interestingly, Lawrence also highlights The Spar, a local, fairly unassuming corner shop, but here too he envisages opportunities for decision-making autonomy in the act of choosing his groceries and planning, preparing and cooking his own meals; decisions which had previously been made on his behalf.

#### *Choosing not to move*

Conversely, it is also important to know more about why PWLD may choose *not* to move. Throughout the research it was obvious that the decision to 'stay put' is not merely one derived from a lack of awareness of other residential options. In contrast, many respondents chose to remain in a particular home as an empowered act of agency which speaks to well-considered and supported visions of their ideal living situation. When asked about his home, Grant (29) states simply, "I'm happy". It is not that he has no independent living plans in the future, but rather he likes the freedoms which living at the family home offer him, such as having his meals cooked for him. Through an honest and supporting relationship with his parents, Grant is content with both the residential options open to him, and his choice to continue to live with his parents, even at an age when many might expect to move into their own home. A critical outsider's view might be that Grant is being infantilised by his carers or simply not challenged to take on responsibilities, but quite the opposite is true. Each time his two non-learning disabled elder brothers moved out,

and when his friends began to move into their own homes, Grant's parents opened discussion with him regarding opportunities for moving into his own flat and each time were met with resistance from Grant himself.

For others, the desire to remain in a certain home or neighbourhood is connected to the memories held within that particular site. Maria (64) explains that her current home was one which she and her parents chose together and "fell in love with". After their passing, Maria was faced with the prospect of having to move into another, smaller home or residential accommodation, neither of which she wanted. Again, with a combination of appropriate support from family and care agencies and an honest assessment of the allowances which would have to be made to allow her to remain, Maria was able successfully to make a decision about her living arrangements; one which permitted her to stay in a house which meant so much to her.

A lack of suitable accommodation also presents as a main reason why some PWLD choose not to move, particularly those who are choosing not to move out of their family home. In Amanda's experience, the residential options available neither met her needs physically, in terms of proximity to services, nor emotionally:

*A: It was a bit strict you know?*

*V: A bit strict?*

*A: Aye.*

*V: Yeh, because other people would have to tell you what to do and things?*

*A: Yeh.*

*V: And you wouldn't like that?*

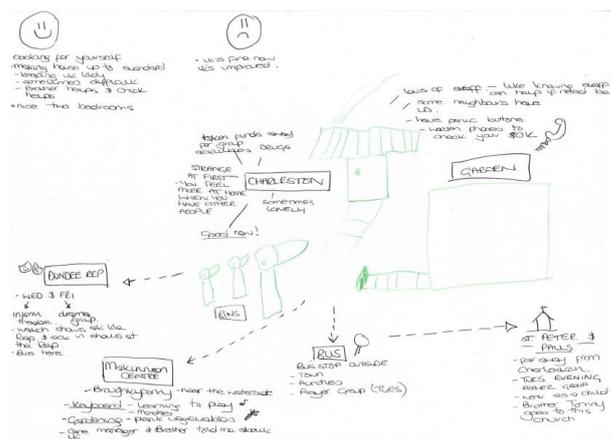
*A: [shakes head] No, I've got too much in my head!*

*(Amanda, 48)*

It is obvious from this interview extract that the accommodation offered to Amanda did not fit with the life that she lived, nor the one

that she imagined for herself in the future. With this residential group home came an institutionalisation of the home space both temporally and physically. Shift changes for support staff would dictate when and where Amanda could go to her various clubs and events, and actually sharing the physical spaces of the home with others could force unwanted social interaction. In contrast to empowering those with learning disability through a supposedly more independent environment outside the family home, it is clear that such accommodation also be restrictive, further stressing the importance of supporting all decision-making, and all possible resulting outcomes, about home.

### Box 2. Case Study with Lawrence



Here, Lawrence (70) depicts Charleston (depicted on a larger scale in Appendix 10), his current home and a place which engenders mixed feelings. It is now, for all intents and purposes, his home in every sense of the word, and he is happy here, but this has not always been the case. The circumstances which led him here and the lack of decision-making he experienced in his residential options, made this move one which continues to cause Lawrence pain and confusion. The reasons why Lawrence had to move from Blackwood Court are not fully understood, part of the issue perhaps, but he tells me that the building in which he lived was due to be knocked down and replaced by more modern facilities. The options then presented were limited: move to Charleston or find alternative accommodation. This news seemed to take Lawrence by surprise and I was unable to get at when and how the subject of moving was broached. Presumably, this decision was not made by the housing association on the spur of the moment, but it seems that Lawrence was not made part of the decision-making process nor kept fully abreast of plans in order to have the required

time to 'come to terms' with, and to prepare himself for, the move. Upon moving, he was led to believe that the shift to Charleston (also a sheltered residential facility owned by the same housing association as Blackwood Court) would be temporary, a maximum of two years to allow the building of new premises. Five years had already passed at the time of interview with no sense that there would now ever be the option for Lawrence to move back to a home in which he had truly been happy and, in fact, the promised building of new housing had never come to fruition. There is a sense here that austerity measures had come into play and the building of the new residencies were no longer financially feasible. As far as Lawrence is concerned, however, he has been left in the dark regarding his future, his main hopes still resting on a move back to Blackwood Court without any indication by his housing association that this may actually ever happen.

Even in the comparison between the lively and numerous descriptions peppered around the drawing of Blackwood Court and the sparse annotations which describe his time in Charleston, Lawrence displays his feelings of attachment rendered inconsequential by a residential move over which he had no control. It would seem that even outwith the institutional setting of the long-stay facility, decision-making, choice and control are not as easily encountered as policies like *SAY?* (2000) and *TKTL* (2012) may have hoped. When discussing Charleston, Lawrence is less emotive in how he expresses his opportunities, repeating "it's fine. It's fine now" after almost all negative comments; a quiet acceptance perhaps that he must make the best of this situation. A key observation here is the inclusion of the bus stop, Lawrence's route out of Charleston, representative not only of his want to remove himself from the surrounding area where possible, but also the decision-making capacity afforded to him in his ability to leave in search of places of importance, such as his church. Decision-making is further impeded in Charleston by the reduction in funding of local groups and clubs which Lawrence had attended, such as his music class, providing still less opportunity for decision-making and increasing his feeling of isolation: he states, "I'm sometimes lonely here". A simple statement of emotion, but one which strengthens assertions that opportunities for decision-making with regards to home are crucial, concerning not only the home space, but affecting how PWLD see and represent themselves and their communities and how they envisage their lives in the future as active and belonging citizens.

### *Making residential decisions*

What is unclear from discussions on why PWLD decide to move home, or not, is where the impetus for such decision-making comes from. Although, where possible, decisions regarding home should be made by PWLD themselves, it is also worthwhile to note that some PWLD, especially those interviewed with more severe learning disabilities, do need input from carers and families if they are to realise that they can impact on decision-making regarding their home. Where familial care structures are missing and those with learning disabilities are legally deemed to lack decision-making capacity, it can fall to local authority social services to make residential decisions on their behalf; and Mary (51) provides an extreme example here. When she was first introduced to the housing charity<sup>60</sup> through which she is housed, very little was known about her past. As an infant, Mary was left on the doorstep of a Glaswegian convent and raised by the nuns there with no existing knowledge of her personal history or any family connections. The closure of the convent, over 30 years later, required social services to find a suitable place for Mary to live. This narrative of learning disabled experience is not easily aligned with what is known of recent social history regarding learning disabled lives, but it is obvious that, without decision-making input from other, non-disabled actors on her behalf, Mary's residential options would have been somewhat more limited.

Some older respondents, like Andrew (58), lack residential decision-making capacity as a direct result of the social discourses surrounding learning disabilities which existed at the time of their birth. As a boy, Andrew was entered by his parents into the residential institution of

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<sup>60</sup> This particular housing charity aims to house PWLD in small group homes with 24-hour care, but I have chosen to leave the charity nameless as the small-scale nature of the charity may render respondents identifiable.

Quarrier's Village<sup>61</sup>. During the course of the interview, he explains how he was moved from house to house within the 'village', dependent on behaviour and age, mediated by those who ran the institution. From an early age, then, Andrew was unable to be a decision-making force in his life. This is not to say that he did not enjoy his time at Quarriers, but it resulted in confusion when it was time to leave the institution and he required new, community-based accommodation. Much of Andrew's adult life has been spent in care home facilities which he finds limiting, and, despite being surrounded by others with learning disabilities, lonely. The aim of deinstitutionalisation was to provide more control for PWLD over their lives and social interactions, but it is clear that choices remain difficult to achieve when those with learning disabilities are not given the tools to engage in the decision-making process.

For others interviewed, decision-making regarding accommodational setting was removed in order to ensure their physical wellbeing. Although Lynne (68) resents her move into her current care home<sup>62</sup>, she is undoubtedly better cared for here physically than in her previous home, where a number of serious falls had taken place. Her lack of participation in the decision to move still has had obvious negative impacts on her mental wellbeing, as narrated earlier in this chapter. Similarly, Lloyd (71) was moved into an elderly care home when it became clear that he was no longer able to care for himself. Unlike Lynne, Lloyd enjoys his residential setting<sup>63</sup> and feels that he benefits from daily interactions with others, even though the choice to move there was not his own. These differing examples of PWLD

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<sup>61</sup> Opened by William Quarrier in 1870, Quarriers village originally sought to care for poor and destitute children in Glasgow by providing housing in children's cottages under the supervision of house fathers and house mothers: a very different mentality to orphanages of the time (<https://quarriers.org.uk/about-us/history/>)

<sup>62</sup> A religious care institution for the elderly.

<sup>63</sup> A relatively small care home for the elderly.

having residential decisions made on their behalf highlights the difficulties in balancing between the promotion of autonomy and the preventing of serious risk to personal safety. This balancing act calls into question the level of risk afforded to PWLD with regards to their residential decision-making.

In opposition to this dimension are those PWLD who decide that it is time to move home. In Wilma's (23) case, she has been the driving force behind the recent decision to move to a home of her choice. This decision has required negotiations between herself and her grandad, who is concerned about her additional health concerns above and beyond her learning disability. Wilma (23) has been supported to understand the compromises that are required in order for her successfully to move out of her family home. Ideally, Wilma envisions herself living in a flat on her own, but worries about the level of input which would be required from care agencies to allow this to be the case. As such, her carers have identified a placement within a residential care home – one specifically geared at older residents – in the area where she wished to live. While her grandad has concerns over a young girl staying in a home with elderly residents, Wilma views it as an opportunity for further independence and new experiences. Most importantly, she feels that this is a positive decision and a step towards the independent home life significant to her.

How decisions are made is clearly dependent on both level of learning disability and the age of the person concerned. Those with the most severe learning disability interviewed for this project have tended to enjoy the least input into the decision-making process and very rarely themselves began discussions regarding the intention to move home. For some, this lack is due to an inability to communicate or express opinion in any form, while others tend to have very little desire to make decisions, perhaps reflective of limited opportunities to do so in

other areas of life. Those with the least severe learning disability have reported a much freer decision-making experience, but with similar restrictions to those without learning disabilities, such as financial concerns. Decisions within these groups are generally negotiated between themselves and spouses, partners or children as opposed to between carers, charities, support agencies and housing services. Those who find themselves somewhere in the middle of the capacity range experience innumerable interspersions of these decision-making routes; some being the catalyst for residential change, others being coerced. What is central is a recognition that, like those without learning disabilities, those with learning disabilities have aspirations, worries and motivations which are reflected in their reasons for making certain decisions concerning home. Opening up communication channels about these issues can not only tell us more about decision-making processes for PWLD regarding home, but also ensures that PWLD are always centralised within decisions about their lives, not merely in thought, but in voice.

#### *Deciding where to live*

Freedom to make decisions about home, moving or not moving tell only part of the story, and so it is key to think about how PWLD decide precisely *where* they should live. Significant to Aimee is the ability to live alone, but in close proximity to her family:

*My mum's just down the road and my sister-in-law and my brother, my big brother, and his two kids, they only live [in the next town], so that's good. They are up the top and I'm in the middle and Mum and Dad are at the bottom<sup>64</sup>.*

*(Aimee)*

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<sup>64</sup> Here Aimee is referring to the three towns which run one after other along a main road and down a hill.

In choosing an area, it was important that Aimee could easily travel to visit members of her family. Though independence was sought, she also wanted to know that she could be easily reached in an emergency. Ideally, Aimee would have moved closer to home, but the reality of house prices in that area reduced her choice of accommodation, and so Aimee and her family have instead chosen a town where the rent is more feasible and transport links allow her easily to travel to her work, local centre and family homes. Like those without learning disabilities, then, residential choices were made here which took into account finance, infrastructure and ambience, resulting in a home space where Aimee now feels safe, supported and independent.

The physicality of the surrounding environment can also impact on where PWLD choose to live. Claire's (51) home was provided by the local housing association<sup>65</sup>, within an area in which she felt comfortable. Asked about the possibility of a move in the future, Claire states:

*I like this block [of flats]. I don't want to go to another block for the simple reasons that I can't walk up a lot stairs neither I can. I can come up a wee bit of a hill but I can't handle stairs, so if I was to move from this house, I would prefer the same block.*

*(Claire, 51)*

For Claire, the physical environment is central to her decision-making regarding where her home should be. Her current placement allows her to maintain the lifestyle that she enjoys, and she feels confident that she can go to the local supermarket or visit with nearby friends without concern for her physical wellbeing.

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<sup>65</sup> Glasgow Housing Association, social housing providers and not learning disability specific (<http://www.gha.org.uk>).

It is not only the house itself which should promote autonomy, but also the area in which it is situated. In a similar vein, it is the physicality of the surroundings landscape which influenced where Darren chose to live:

*It's not a big village. That's the good thing about it, it's a small village. It's better for disabled people than a big town like Glasgow because in Glasgow you don't meet these people, you don't meet anybody. Because I know people in Glasgow and they don't get seen like what we get in the small village. A small village is better because you get to know everybody and everybody gets to know you.*

*(Darren)*

In Darren's experience, he prefers to live in a smaller village, feeling that he is more visible as a learning disabled person within this environment. Rather than a desire simply to blend in, Darren feels empowered by the fact that those around him know of his learning disability and offer to help and support him where needed. He would argue that his learning disability makes him vulnerable, but that living within a small village, where he has regular interactions with non-learning disabled groups, renders him a visible but legitimate, accepted and assisted community member in a way that he did not experience living in larger towns. Here, Darren arguably buys into the classic *Gemeinschaft* sense of village communities whereby small-scale living in the rural setting breeds familiarity and intimate, comfortable and supportive bonds with others who live in close proximity (Parr and Philo, 2005). These *Gemeinschaft* social relations are, Parr *et al* (2004: 414) highlight, something of a double edged sword, since "closeness can also spur efforts at distancing while intimacy can go hand-in-glove with repulsion", so rendering the learning disabled individual visible as a subject of ridicule and local gossip. For Darren, however, his decision to move to a village has, by

his own admission, had positive effects on his mental wellbeing and confidence.

It is not always the case, though, that those with learning disabilities and their families are able to choose where they live. William's family had a different route into their current living situation compared to that experienced by both Claire (51) and Darren. Between himself and his late wife, William's father has always been his main carer. Living within the family home has required many adaptations, such as pulleys and wet rooms, properly to allow them to care for their profoundly learning disabled son. However, when William's father also became physically disabled, their home was no longer suitable for two wheelchair users and, as such, the family applied to the housing association for a move to more suitable accommodation. Although they were given a wheelchair accessible home, the family were unable to make decisions regarding the area to which they would be moved, but rather were presented with a 'take it or leave it' option. The home itself presented opportunities for a more independent home life for the family, but posed problems for wider care structures in place for William (27). Having no decision-making capacity in deciding where they lived then resulted in disruptive changes to access service provision which was close to their new home. Once more, it can be seen that decision-making for PWLD and their families regarding where is home can be a choice between the lesser of two evils. Despite regulations which state that all housing estates require a mix of social and private housing suitable for those with and without learning disabilities, William's family was moved beyond their familiar area to accommodate their needs. The consequences that moves such as these can produce must be considered in their complexity, and not simply left to the families to re-organise, re-shuffle and make allowances for.

For other respondents, the opportunity to decide where to live is something that was never considered. The 'where' of her accommodation for Eilidh was not as important as with *who* she lived. Her preference was to live with her parents and the surrounding area was of no concern. Likewise, Paul (62) had no preference where his home was, so long as he had the chance to live independently with the correct support structures in place. Allowing PWLD to decide where they live involves an intricate web of physical versus emotional needs, and it stands to reason that many of these needs, as for those without learning disabilities, cannot always be met in their entirety. It is nonetheless essential that those with learning disabilities feel that they are considered part of decision-making about their home lives, with a realisation of how these decisions can impact upon them more widely.

#### *Emotional attachments to home*

Taking into account these diverse experiences of choosing, deciding and being heard with regards to decision-making about home, it is worth appreciating how those with learning disabilities think about the home spaces in which they reside. Emotional attachments to home spaces say a lot about PWLD experiences of finding a place to stay and creating memories there. When discussing living in their own home, many respondents spoke of feeling pride in their home spaces:

*I like to have a beautiful house and watch my tele and keep my house clean. I like to have a nice clean house and [to] sit and watch [television] in my comforts.*

*(Stuart, 42)*

Stuart feels pride, not only in having his own home, but also in his ability to make decision about that homespace; to make it into a stylish place where he can feel comfortable and relaxed. He views his

home as an extension of himself, and so gains pleasure in saving for home improvements which he thinks reflect his healthy state of mind and desire always to better himself. Having the drive to influence his home surroundings is empowering for Stuart and illuminates the importance of continued decision-making regarding a home, even in the minutiae of the decorating and up-keeping of it. Similarly, Mae (50) exudes extreme pride in her ability to maintain a clean and well-decorated home, even though she lives in an area which she feels is not ideal (in terms of those who live around her). This pride is derived not only from having an independent home as a learning disabled person, but in a promise which she made to her late grandmother to save and set herself up on her own, out of the family home. Having willed her the money for the deposit for her flat, Mae feels that she owed it to the memory of her grandmother to maintain an independent home for herself which reflects her success as a learning disabled person. Having familial support, in the form of her grandmother's belief in her ability to maintain a home, has allowed Mae easily to make decisions regarding her living arrangements. This furthers her confidence and drive to live the life that she wants above and beyond her learning disability.

For Kim (47), the freedom with which she feels she can make decisions about home affords her a positive attitude about moving on when a house no longer suits her needs. When moving to her current flat, she explains that she wanted "somewhere different to go", prioritising having "some space for myself". Home, for Kim, is therefore a place which opens up possibilities for travel near and far, a place which she can decorate to her standards and about which she can feel at peace with herself. With no perceived barriers to decision-making holding her back, Kim feels fully able to participate and make a difference to her community through volunteer work with her local church, thus illustrating the empowerment which can be found when home, place

and decision-making work together to create positive changes and opportunities.

This is not to suggest that deciding to stay in the family home with parents does not have an emancipatory effect for some PWLD. Paul (62) enjoys living at home with his mother and father, appreciating the freedoms this gives him. With extended family and friends nearby, Paul feels comfortable navigating his local area. He views home as an anchor point, a fixed and stable point to reach out spatially into the world, from which he is able further to explore opportunities for work, recreation and friendship. Moreover, Paul has positive feelings towards future prospects for moving into a home of his own, like his non-learning disabled brothers before him, which are not hindered by his current decision to live at home with his family.

As has previously been mentioned, lack of decision-making can also breed negative associations with the home space, emphasising the imagined binary between what is considered *house* and what is considered *home*. Lynne (68) in particular expresses deep resentment at being in the residential care home where she lives. Although she is surrounded by trinkets and photographs of family members, she does not consider it home; rather, it is somewhere that she is resigned never to escape. These feelings stem not from her wish to be elsewhere, as such, but from her complete lack of control over the initial decision to be moved into the care home and, more so, her subsequent loss of control over immediate surroundings and who has access to them. Home for PWLD is not simply about control over the aesthetics of the physical surroundings, but sits in a deeper connection to the spaces and places of a particular house within a specific environment as felt by the individual.

## **The art of decision-making**

It is apparent through observations within this chapter that experiences of decision-making and home vary widely. These realities are highly dependent on the person with learning disability's age, level of learning disability, family support structure and the personality of the individual. Decision-making, it can be seen, is not an inherent skill or trait, but one which many PWLD need to learn and to have the opportunity to explore. The decisions being made may be minute or life-altering, but, without the opportunity to make them or at least be meaningfully consulted, PWLD cannot be in the driving seat of their own lives. It is indeed 'risky business' to allow PWLD to make a decision regarding something which they may or may not fully understand, but it is crucial to their rights as a person, learning disability or no learning disability, to be able to make mistakes. It stands to reason that PWLD will make the wrong decision from time to time, and that these mistakes may have serious implications. However, the chance to be wrong is not something that should be denied. Worryingly, it implies that those of us without learning disability will always make the best decisions; this is clearly not the case. It is also recognised that some PWLD cannot and will never make decisions, nor fully understand the consequences of their choices, but this does not deny that, where possible, all attempts should be made to include learning disabled voices and opinions in decision-making regarding their lives. Learning disabled lives involve, at all levels, an intricate network of people who, for the most part, work to appreciate and better the lives of those with learning disabilities. At a policy and governmental agency level, however, there is an obvious detachment wherein PWLD are partly, if not wholly, missing from decision-making processes which impact on their abilities to undertake those things that they can do, like to do and may wish to do in the future.

## Chapter 6

### Movement

The practice of movement speaks to a number of different ways in which people can interact with, and have influence over, the spaces through which they travel. This chapter therefore utilises in-depth interview work to focus on how PWLD experience movement on a variety of scales, as they undertake the everyday activities of their ‘abnormally normal’ (Hansen and Philo, 2007) lives. Very simply, it aims to demystify the daily interactions and longer-term migrational histories of PWLD, by understanding the ‘why’, ‘where’ and ‘when’ of movements made; movements and implications made all the more clear by the case-studies which punctuate the narrative. Crucially, the research also identifies the highly subjective reasons why many PWLD feel restricted in their ability to influence and enact certain types of movement, giving special attention to the unpredictability of mobility which many PWLD find overwhelming. Moving forward, the chapter explores the notion of ‘just getting out’, whereby movement becomes a cathartic, maybe social experience which subverts the routine expectations of learning disabled life. Lastly, the chapter concludes by drawing out the specifics of movements *within* the home space, making clear the movements that ‘home’ affords above other places in which PWLD spend their time.

#### ***The why, where and when of movement***

It is perhaps obvious to suggest that many PWLD have similar daily or weekly configurations as those without learning disabilities. Many PWLD also put time aside to shop for food or to enjoy recreation, they work or volunteer, and they make time to see friends and partake in hobbies which they enjoy. What is perhaps different, though, are the ‘patterns’ in which these movements and interactions take place. For some, these movements are done alone but, for the majority of those

interviewed, these movements include, and in many instances are instigated by, parents and carers. Work hours are irregular and rarely paid, while hobbies are usually undertaken during the day within centres or groups run specifically for those with a variety of learning disabilities. How, then, do those with learning disabilities imagine the daily interactions and connections which they perform?

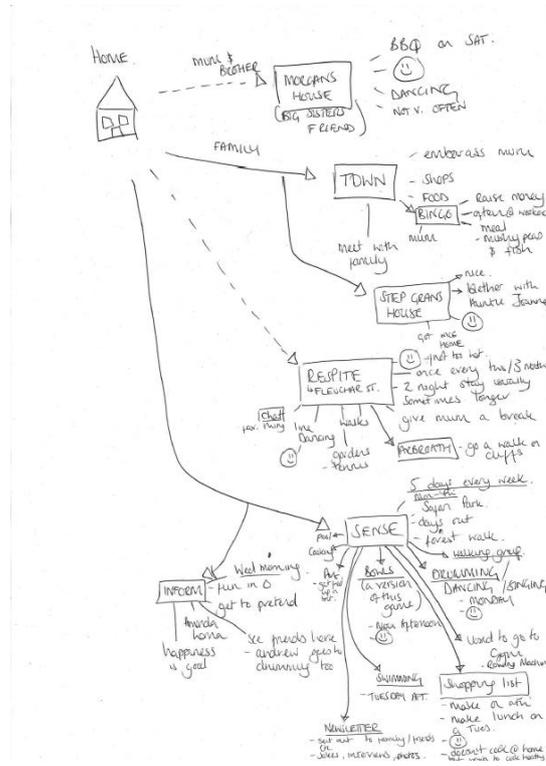
Figure 18 below shows a network map devised in a workshop interview carried out with Scott (20), a young man with learning disabilities who attends Inform Theatre Group in Dundee. Throughout the interview we discussed his home and the places to which he travels within his community on a regular basis. The lines do not indicate geographical proximity to home but, rather, the order in which he remembered the places which he likes to go, and the connections that he imagines between them. Scott (20) splits these locations into three distinct groups: places he travels to with family; time spent at Respite<sup>66</sup>; and time spent at centres and groups. For each space we discussed emotional attachments, social interactions and the specific movements and mobilities encouraged in each space: for example, a 'blether' with Auntie Joanne at his step-gran's house or cliff walking in Arbroath with Respite. While able openly to discuss the movements which take place within these localities, very little attention was paid to the actual ways in which he travelled to each place. Such travel was therefore viewed as an inconsequential must, an unthinking act necessary to reach places of interest.

This theme was common for many respondents, who often ventured nothing of the tensions inherent in the act of travel without being specifically asked about their feeling towards it. What is instead

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<sup>66</sup> Scott attends a residential Respite for PWLD two nights each month where they also undertake a number of day time activities.

obvious from Scott's account is the sense of routine which can be gleaned from the specific 'when' of his movements: shopping on a



**Figure 18** Showing Scott's network map of the places he likes to go and the people who he likes to visit. Reproduced in large-scale in Appendix 5.

Tuesday; Inform Theatre Group on a Wednesday; weekly bingo trips. Access to activities like those mentioned by Scott (20) are facilitated by his care team who essentially act as his Local Area Coordinators, carving out places and spaces for Scott to go in which he can be himself (Hall and McGarroll, 2013). Whether or not these spaces and places are available and accessible depends wholly upon where a PWLD is living, highlighting the connection between residential location and opportunities for movement in the community. Moreover, this point further emphasises the uneven landscape of care and provision of services across and between local authority

boundaries. The chapter turns now to consider how influential is such regular activity for those PWLD consulted in the research?

### *Routine*

A key facet of care received through care companies and charities, as highlighted by respondents, is the regularity and repetition of activities, clubs and groups, which create set routines for PWLD to follow. Carol's mother gives a sample of Carol's (29) weekly routine with her care provider:

*Tuesday she goes to a computing group [with her care provider] in the morning, and she goes to the [local] health and fitness place, gets her lunch there. That is all [with her care provider], it's special needs too, they go there as well, so it's all her friends.*

*On a Wednesday she only goes out at 1 o'clock [with her care provider] and it's fitness, healthy eating and fitness; it's just a friendly wee group sort of thing.*

*Thursday morning is one-to-one and she either goes to the [exercise] bikes one-to-one at Glasgow [local gym] and that's an hour and she gets her lunch. She's only got two hours on a Thursday so she comes back after that.*

*Friday, she is out again [with her care provider] for yoga in the morning and in the afternoon she goes bowling and is back for two.*

*(Carol's Mother)*

The schedule described above is one recognised by the majority of respondents, with most able to tell me exactly where they would be and at what time during the average week. For many, the provision of regular movement such as encapsulated here ensures a variety of experiences, a chance to learn and the opportunity to socialise. Routine can provide safe and familiar routes through life which appeals both to carers and PWLD themselves, who often find it stressful or intimidating to be faced with new and unfamiliar people,

environments and activities<sup>67</sup>. From the perspective of the carer, regular, pre-agreed and pre-arranged routine is a way of 'ticking the care boxes', ensuring that set hours are given and an assumption met that adequate care at personal and social levels is being received. This claim is not to deny that a good quality of life may genuinely be ensured in the process, but there is a very real fear, evidenced by the closure of three day centres in GG&C, that opportunities will be withdrawn or financial support rolled back or completely cut.

Even for those outwith the structured provisions of care companies, having regular patterns of daily activity creates purpose and often fights the monotony of daily life within the home:

*Where [her husband's] work is, there is a café and swimming and all that in it. We go there quite a bit as well. That's how I lost the weight, by going to the swimming. I have two pounds to lose and that's two stone I've taken off.*

*(Barbara, 48)*

Movement to the café itself provided Barbara with an opportunity to leave her home, something important to her, as other co-morbidities impact on her abilities to move independently around her community as she would wish. More importantly, the opportunities for movement when in that space, in particular swimming, allow Barbara to work towards personal life goals. Losing weight<sup>68</sup> means that she is able to put herself forward for much needed hip replacement surgery, which Barbara feels would change her ability to do the things that she would like to do, and to visit the places that she would like to visit. It is clear, then, that opportunities for movement are as important as the movement itself.

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<sup>67</sup> Again, most of 'us' without learning disabilities also like to have routines and are hesitant about moving outwith our comfort zone.

<sup>68</sup> This, of course, links to prevailing health discourse about PWLD, weight gain and the need for regular exercise (Melville *et al*, 2007; Hsieh *et al*, 2013; Koritsas and Iacono, 2015).

### *Opportunities for movement*

In order for those with learning disability to move about their daily lives interacting and living, there must be opportunities for movement in easily accessible and obvious spaces, through which they feel happy and comfortable travelling. Utilising public transport and having access to walkable areas are ways in which differing scales of geographical movement can be experienced by those with learning disabilities, be that short term, such as going to the local shopping centre, or longer term, such as going on holiday. Mae (50) explains: “[t]he bus stop is just across the street and it is easy to get into the town at night, and the dam<sup>69</sup> is just down the street where I can go for a walk and there is shops just round the corner”. Having prospective places which she knows she can inhabit in her own time affords Mae confidence in her movements, opening up possibilities outside of the home which suit her and her (often altered) time scales. Not only is Mae able to pinpoint local places where she is happy to spend time, but she is also able to adapt what she knows about these localities to other places which require a little more travel; and hence her routine is the platform for occasional more adventurous trips.

Movement can also be encouraged and developed through attendance at different clubs and groups which often require that PWLD are, initially at least, pushed out of their comfort zone and into new and unfamiliar environments. Darren (42) talks about his experiences of navigating different areas in Glasgow:

*D: Well I know the area because I did my gardening up there.*

*V: Oh did you?*

*C: In Growing Concern<sup>70</sup> [...] it's about plants and we grow plants and did all sorts of gardening things up*

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<sup>69</sup> This refers to Murdieston Dam lake where many local residents meet to walk.

<sup>70</sup> Growing Concern is a college run gardening vocational course.

*there, driving tractors and grass cutter and all that kind of thing, and I worked hard at that and I got my qualifications there for gardening, and for City Guild<sup>71</sup> as well.*

*(Darren)*

Through participation in groups such as Growing Concern, Darren was forced to go into new and different locational scenarios in order to undertake the things that he enjoyed. Through support and guidance, he opened up his social world, taking in new geographical experiences and fulfilling his desire to gain qualifications, pushing the boundaries of where he was happy to travel and how comfortable he was when he got there.

Given the opportunity to travel and to explore (locally or otherwise), most respondents do so, but it is also pertinent to note that alterations to previously available opportunities can have an impact on when and where people are able to move. Grant (29) and his mother discuss the changes that have taken effect in his access to college:

**Mother:** *What's been cut this year [Grant]? How many days did you go to college last year?*

**G:** *I had more than one [a week].*

**Mother:** *What was the problem?*

**G:** *Age...*

**V:** *So you used to go to college two days a week and they've cut that back to one day?*

**G:** *Yes*

*(Grant, 29)*

While Grant was keen to continue working towards his qualifications at college two days a week, changes in his personal circumstance, on this occasion his age, have had significant ramifications upon the opportunities available to him, despite the fact that his needs and wants have not changed. These changes have left a gap in Grant's

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<sup>71</sup> City Guild provide skills, qualifications and jobs to ensure that people can contribute to successful businesses and economies by working with education providers, companies and governments (<http://www.cityandguilds.com/about-us>).

week, therefore reducing his social mobility and ultimately removing his choice and decision-making capacity regarding where he can and cannot go, an issue tackled in Chapter 7. Furthermore, Barbara (48) expresses feelings of frustration regarding her current learning situation,

*It is just a pity it is only one day a week with two hours on it. Do you know what I mean? If we could get it, a wee bit more way with, but obviously our tutors have others classes as well so you can't really.*  
(Barbara, 48)

The tightening of budgets and lack of staffing mean that Barbara does not have the opportunities available that she would wish, and nor is she sure who she should speak to about upping her hours of learning. For her, this deficiency of opportunity for movement results in her spending more time at home than she is comfortable with, in a space where she can feel both isolated and trapped. Without the provision of opportunities, or ample opportunities, as is the case for Grant and Barbara, those with learning disabilities will lead increasingly sedentary lives, negatively impacting upon both physical and mental health, social worlds and experiences of independence.

### *Proximity*

A key feature which continues to impact on personal mobilities for those within the research are the proximities of the places where they might like to travel relative to their home spaces. For many, dependence on public transport, other co-morbidities and perceived feelings about the spaces around them make proximity a keen issue. Distribution of the services provided means that day centres and community centres are usually fairly close to home and, more often than not, travel services, be that taxis or buses, are provided to get those with learning disabilities to where they need to be. What is of

interest, then, is how and why proximity impacts on the social lives and experiences of learning disabled individuals.

When talking about friends, Barbara (48) explains that she has many friends, but “Anne and Claire (51) are nearer to me” and therefore it is easier for her to see these friends most often. Friends who perhaps live a few streets away are considered ‘luxury visits’, even though this is a distance which, for many non-learning disabled individuals, would not be considered far. For the purposes of the research, these visits have been termed ‘only if’ visits; only if a taxi can be afforded, the bus travels down a particular road or someone is free to drive there. These restrictive proximities appear only to occur for those PWLD without the means to travel independently due to either physical or mental health issues with regards to movement. Moreover, these proximities are often complicated by the fact that some PWLD are unable to choose where they live and, as such, how close they remain to friends and family. Similarly, Amanda (48) speaks about the change in relationship between her and certain family members, impacted by a change in their proximity, saying, “well [her sister has] moved into the neighbourhood so we see her a bit more now”. Previously, Amanda’s sister had lived further away than she could easily travel, and, furthermore, the flat in which her sister had lived was not easily accessible for Amanda’s walking needs. Proximity, then, is an important consideration in the decisions made regarding movement and mobility opportunities for PWLD. How PWLD feel about the spaces around them and the distances to where they might like to go then become significant facets of everyday learning disabled life, which it is important to understand and account for when considering how those with learning disabilities feel about their home environments.

### *Non-movement*

Alongside thinking about the where, when and why of movement, it also vital, as Barbara (48) mentions (above), to discuss the reasons why some PWLD are not mobile. For Aimee, her frustrations at her lack of mobility arise when she stays home:

*V: Do you like staying yourself?*

*A: Eh ... some of the time but sometimes I get bored and try to get something to do[.]*

*(Aimee)*

While there are many clubs and activities which Aimee can, and does, access during the day, she feels that there is very little to do at night which would keep her entertained. The differing mobilities among Aimee and her various learning disabled friends means that visits and social events are rarely spontaneous, leaving Aimee feeling disengaged from those around her with whom she shares interests. It can thus be seen that it is not only the mobilities of PWLD themselves which can impact on their movement, but also the mobilities of those around them.

Conversely, Carol's (29) experience of non-movement is one which derives from her desire not to socialise, as her mother explains:

*She will socialise with us but we have to encourage her because she will spend all her time in her room if she could get away with it [...] Since her dad died she has not been as friendly, she wants her own company now more or less which is not good.*

*(Carol's Mother)*

It is clear that grief has impacted heavily on how Carol feels about certain types of movement, and this emotional state manifests in her keenness for her own company. This is a worry for her mother, who wants her daughter to be a confident and mobile individual outwith the family home. In particular, Carol's mother worries about what

would happen to Carol's mobilities, and the resulting experiences, if she, her mother, were not around to encourage and to develop them alongside her care providers.

The mobilities of those with learning disabilities are clearly defined in most cases by routine movements centred on the provision of care and support, ensuring that, where possible, the minimum amount of care – and if possible, more than minimum – is received by those who need it most. Regularity provides opportunities for movement which can encourage movement for some while hindering movement for others. Proximity also features as an influencing factor on the where, why and when of movements made or, indeed, not made. On that later count, it is important that the research pays further attention to those things which restrict movement for a number of learning disabled people.

### ***Restrictive movement***

Restrictive movement in this instance refers not to restrictions in available opportunities for mobility, but to those mundane reasons discussed throughout the research which influence how and when PWLD choose to move or not. Of course, couching it as a 'choice' may indeed be misleading: for some, there is no conceivable range of options from which to 'choose'. These limitations are experienced within the routine of care structures or due to co-morbidities, age or even the time of day. For others interviewed, the limits to movements experienced are embedded within concerns over the unknown variables which could be encountered within the surrounding environments through which they travel. These variables may seem almost too mundane, too recognisably 'normal', but are nevertheless crucial underpinnings which tell us more about how PWLD manoeuvre through the practicalities of everyday life.

## Care

As evidenced in Chapter 5, care can be a freeing experience for many PWLD, opening opportunities which were either previously unavailable or simply unknown, but it can also be the very reason why some PWLD feel restricted in their daily movements. Maria (64) explains how her care regime influences her wider mobility within the community:

*We did have another shift, it was a lunch time and it knocked me off and I couldn't go out in the afternoon because it was too late. I was stuck so they stopped that [...] I like to go to the [shopping centres] and I couldn't do that because I was so late with my lunch and that was why they stopped it. I was quite pleased they stopped it.*

*(Maria, 64)*

Moving about in her daily life had become problematic for Maria, as the shifts of care which she received did not leave any flexibility in the time of day at which she could receive help. Although grateful for the assistance she receives, the required rigidity of her access to care led to Maria becoming less mobile and so less able to spend her time in ways which she felt were appropriate. Removing this portion of her care allowed Maria more mobility and, ultimately, more independence which, in turn, leaves her feeling content, positive and in control of her life.

This change, however, is not always the case and, as Robert's father explains, there are times when the care offered does not support the movement sought by the PWLD themselves or their families:

*One of them came back and he said 'we took him, oh he got a bit stroppy' and I said 'what are you talking about?' and he said 'he came out of B&Q' and I went 'what?', you know the leisure centre up here, there's a retail park, he said 'when we came out of there he was trying to run away.'. 'I'll tell you now', I said, 'don't ever take him there again'. If you took me in*

*there I would run away [as well]! They thought it was a big deal him wanting to run away and I said 'well what would you do if someone wanted to drag you around B&Q, you're supposed to be going out!'*

*(Robert's father)*

In this instance Robert's father is incensed at the notion that a trip to a hardware store should suffice as a day out for his son. Examples of care such as this one indicate the apparent prioritisation of *any* community mobility as a fulfilling experience, over and above enjoyment in the act of moving or the outcome of movement. What is not clear from the described exchange is whether or not Robert's trip to the hardware store was considered a piece of 'community work' by Robert's carers, whereby they felt that he was being given skills for the future.

Robert's lack of communication would suggest that this objective had not been the case, but, it still signals wider issues about what such activities *should* be about, calling into question the neoliberal focus with all activities being 'useful'. As Rose (1999:138) explains, neoliberalist views are such that all activities are "reconceptualised along economic lines", negating those activities which are 'just for fun'. This point echoes arguments by Thomson and Philo (2004) with regards to the 'problematic' of children's play only being valued when fitting with an adultist construction of a child's time well spent, opening yet further troublesome parallels between children and PWLD. Attached to these ideas of 'useful activity' is Cooper's (2016) contention that, in a neoliberal context, the term *fraud* too easily "gets stuck" to ideas about disability and learning disability (Ahmed, 2010:10). People with disabilities and learning disabilities are more open to accusations of fraudulence, Cooper (2016:132) argues, since they already constitute a "site of suspicion" by occupying a body which, in its very existence, encapsulates dependency and denies self-

sufficiency. In Robert's example there are clear discrepancies between parent and carer expectations of 'going out' and the movements which this 'going out' *should* involve.

### *Co-morbidities*

Movement can also be restricted by those ailments which affect people alongside their learning disabilities, as evidenced by the in-depth interviews carried out within this study. These ailments can impact directly on either their ability to move or on how they feel with regards to the practice of moving. When asked about leaving the residential home in which he lives, Lloyd (71) tells me "my legs, I can't walk right you know". Despite the fact that this leg problem negatively impacts his mobilities, Lloyd is happily resigned to the fact that his social worlds are becoming increasingly smaller, feeling that at his age he is comfortable staying within his immediate environment, surrounded by people he calls friends and staff who can offer help at any given time. Wilma's latest experience of having seizures associated with her learning disability has changed how she views her own scope for mobility:

*I was actually coming back from the toilet and then suddenly I felt myself getting really dizzy and, see when I fall, it's like a wardrobe falling you know, I go down with a thud and usually grandpa hears me and runs straight up. But [on this occasion] he never came up. And see when I come round I usually have arms round me and I never felt any arms, I just came round and there wasn't anyone. That's weird. Grampa usually comes upstairs, and that's when it actually hit me, that's when I actually realised that grandpa might not always hear me.*

*(Wilma, 23)*

Prior to this episode, the presence of Wilma's grandpa at her times of greatest need was assumed; it simply had not crossed her mind that, for whatever reason, he may not be on hand to lend assistance when

needed. His absence in this case, about which he harbours guilt, caused Wilma to rethink her mobile practices, questioning her safety should someone not be nearby to provide aid or comfort when she was unable to look after herself. This new found sense of vulnerability changed Wilma's perception about safe movement within the home space and beyond.

Others, like Stuart (42), feel pinned down by their disabilities and co-morbidities, citing them as reasons why they choose not to move around in their lives as they would otherwise like:

*If I could go out and read and write, I would get out my bed every morning and go and work hard like any normal person, and I can go to the bank and get a bank loan so that I can go out and buy a motor or whatever. The only thing that stops me doing my driving test is because of my dyslexia and I fell off scaffolding when I was a really young boy, or I would go out and do all that.*

*(Stuart, 42)*

Therefore, Stuart chooses to restrict his mobility, by basing what he feels he can and cannot do on his impairments, as opposed to focussing on those things he does have to offer. Since the death of both his mother and fiancée in quick succession, Stuart has chosen, perhaps quite understandably, to restrict his social circles, spending most of his time alone. The blow to his confidence which these events have dealt has, unsurprisingly, had a profound effect on the scope of Stuart's everyday movements. While both Wilma (23) and Stuart's restrictions are somewhat self-imposed – in effect, closing down their own options for movement – they are nonetheless vital to understanding more about how and why PWLD experience movement.

## *Environment*

Further factors which do now, or have previously, impacted on movement for PWLD are those environments through which they make their movements. These environments impact on movement patterns, taking into consideration social perceptions in certain spaces, the time of day at which these movements can take place, and even more mundane issues such as the influence of weather conditions. Ronald discusses how policing practices have altered how he feels about travelling through his local town:

*[E]ver since from June [...] I'd say between the end of the year it's not too bad now but I would say this year it's really better than it was. But you know yourself, there's police about more often and you can go down to the town now and they [people causing trouble] can't do nothing now so I'm happy about that now.*

*(Ronald)*

Although he knows his surroundings very well, Ronald had previously felt unsafe travelling around certain areas alone, which had restricted his community mobility. An increase in police presence, combined with a noticeable crack-down on petty crime, means that Ronald now feels more able to travel through local environments. These feeling could be true of any resident in the area in question, given its associations with gang activity and drug use, but it is vital to understand exactly how these activities are perceived and reacted to by those with learning disabilities, who may already have certain social anxieties. It is yet another key piece in learning more about how PWLD feel about their homes and the areas in which they live.

Perceived safety in the spaces around their homes continued to be topic of conversation for those taking part in the research. In

particular, Jamie discusses his feelings regarding activity on certain streets in his vicinity:

*It's alright, this street is alright, this street is okay. If you go down the other streets, you can't walk down them, you can't walk down the streets, especially Victoria Road [...] Can't walk down Alison Street, because of the Romanians and that kind of people<sup>72</sup>; you can't walk down there because they ask you what you are doing. At night time we walk down [a different street] because we can't walk down Alison Street because they watch you, watch what things you are doing.*

*(Jamie, 52)*

It is clear to see that mobility decisions for Jamie are made around the dangers which he feels are apparent. The social actors at work within these spaces determine how Jamie views those particular areas, and so he is able to outline a geographical 'map of safety', an altered form of mobility which reflects the imagined social construct through which his life is lived. Whether or not the threats felt are ever likely to cause real bodily harm is hard to judge; but what chiefly matters here is how these sensitivities develop and lead to restrictive movements which impact on where PWLD go and when. This perception is pertinent when considering the closure and movement of services. It is not, then, merely a case of a PWLD's proximity to their services, but how they feel about passing through the spaces required in order to get to them.

Darren (42) has also experienced influential social experiences in certain spaces which impact on where he is comfortable living and spending time:

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<sup>72</sup> What is clear from Jamie's observations here is that PWLD are just as capable of harbouring negative (maybe even racist) stereotypes about social others as the rest of 'us'.

*V: So why do you think people [with learning disabilities] feel more vulnerable in busier cities?*

*D: Why? Because they get a lot of name calling and lots of things said to them.*

*V: And has that happened to you as well?*

*D: Oh that's happened to me in Glasgow, oh yes, you can walk down Glasgow and you get shouted a lot of names and called a lot of names and you just ignore it. Because you're disabled.*

*(Darren)*

The bullying which Darren has received when traversing the city has impacted on the scales at which he feels he can safely move. Within the small town where he now lives, he is an active member of the community, in which he feels recognised and safe, as explained earlier for his case. Larger cities on the other hand, including the likes of Glasgow City centre, prove too unpredictable and therefore dangerous for him. Similarly, it is knowledge of the environment which influences how Claire (51) feels about her own mobilities:

*C: I mean I enjoy my journeys out, I mean I can only go so far, talking travelling and that, I can only go as far as McDonalds, to Butterbiggins<sup>73</sup>, to Florence Street, I can't go any further than that myself neither I can.*

*V: Why not?*

*C: Cos that's the areas that I'm used to [...]*

*V: So do you prefer to go places you already know?*

*C: Aye aye*

*(Claire, 51)*

Again, Claire is able to triangulate exact locations between which she feels most comfortable moving (a notion explored further in Box 3 below), indicating imagined boundaries over which, should she transgress them, she would feel uncomfortable and threatened. Lack of experience in areas outside of her knowledge restricts where Claire

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<sup>73</sup> A nearby street identified as safe

would travel alone, and so she often remains at home where she can feel more in control, again affecting a version of what we all 'feel'.

### Box 3: Case Study with Lawrence

Given that Lawrence also has a walking impairment related to his learning disability, environment plays a key role in how he is able to experience movement, changing the ways in which he interacts with the everyday spaces which he encounters.



As part of his photo diary, Lawrence produced this image of the walkway leading to Dundee Repertory Theatre, explaining "I've got to walk here because there's a ramp. The stairs are too hard". The physicality of the built environment has not gone unmentioned in disability geographies (see Imrie, 1996; Gleeson, 1996), but what Lawrence reveals here is something of the affectual qualities of the space, stating, "I like the rockery and the plants, they give off a nice colour", and also expressing a wish that they had this set-up at the front of the building for everyone to enjoy. Moreover, this walkway represents an opportunity for transgressive movements, and Lawrence explains that his brother actually prefers that he uses the front entrance of the building, as the ground is more stable, but that he often use this back entrance anyway. This particular space may seem distinctly unworthy of discussion, but underlines a relationship between movement and environment which shines a positive light on experiences of movement and decision-making, further reiterating that it is not the job of non-learning disabled others to be prescriptive about the environments which *should* encourage independence, inclusion and an overall high quality of life.

### *Timing*

In addition to concerns over unknown environments, Claire (51) also explains that she would be apprehensive about visiting some spaces, ones in which she is generally comfortable, at certain times of the day. Similar anxieties were also discussed by a number of respondents with reference not only to the time of day, but to time of the week or year, suggesting that different timings are important in restricting places where PWLD travel through or to which they travel. In particular, darkness plays a key role in reducing mobility:

*W: If I need to pass [a pub] at night I'll probably need to have my grandpa or a staff member with me.*

*V: Ok, and what worries you about that?*

*W: Well, you know in the news you get people raping others and stuff? Well that's why.*

*(Wilma, 23)*

Passing the same space during the day seems less fearful to Wilma, but at night passing by a pub causes stress and fear of serious assault. Indeed, the links between alcohol and sexual abuse have not gone unconnected (see Abbey *et al*, 2003; Ullman, 2003), nor the geographies of women's fear of violent crime in certain spaces (Valentine; 1989; Pain, 1997), but Wilma's fears do prompt questions about the sources of her knowledge and maybe the power of the media to impact on the movement of certain people in certain places. Similarly, John worries about what might happen to him in certain places of darkness, stating: "Sometimes at night there's gangs hanging about, I just walk away and [don't] wrong anybody but there's shouting and calling me names all the time"<sup>74</sup>. These negative experiences, be they perceived or real, impact on exactly when PWLD feel safe to move, and therefore they become restricted to travelling

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<sup>74</sup> Hate crimes against disabled people are well documented: see Sherry (2000), Fyson and Kitson (2010), and Thomas (2011), for examples.

at specified times. This restriction becomes particularly problematic during the winter months as darkness begins to settle even earlier in the day. For Aimee, it influences her decisions about both where to travel and how to get there. During the day she would walk to where she needs to be, but explains that during the winter she either returns home before it gets dark or uses a taxi service. This option not only has economic impacts, since taxis are expensive and budgets are already stretched, but also has social impacts because she will often leave a place early or avoid going there at all if it means travelling home alone in the dark. These factors are not only restricting but potentially isolating, especially in a country like Scotland where winters can be long and severe.

Alongside darkness, weather was commonly mentioned as a reason why PWLD can be restricted in their movements. Many respondents, including Maria (64) and Mae (50), speak of poor weather as contributing to their lack of movement, noting walks or visits happening most often when there is less wind and rain. Some, such as Grant (29) and Wilma (23), have specific weather conditions which cause concern, such as ice, having previously fallen or slipped, so impacting on their confidence in their ability to be mobile in such conditions. These factors affect those without learning disabilities or course, but, like with other marginalised groups such as the elderly<sup>75</sup>, can greatly impact their ability and confidence in moving around their local environments, further affecting their social lives and mental and physical wellbeing.

It is therefore crucial to understand the myriad of deeply personal ways in which PWLD can be restricted in their ability and opportunities to move. Restrictions can be applied from outwith, such as through

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<sup>75</sup> See Hopkins and Pain (2007) and Milligan (2012) for classic geographical accounts of geographies of the elderly.

care structures or due to the actions of other social actors who may negatively impact on their wellbeing. They can also be applied from within, since many restrictions are subjectively understood and developed from ideas about perceived dangers or shortcomings, often related to individuals' learning disabilities. It is a 'dialectic' between the external and internal factors which is at issue here in the same way that it is for all of 'us', but arguably with a particular intensity and potential seriousness of the implications for PWLD. As such, in order properly to provide for PWLD physically, mentally and socially, it is key to be aware of these, sometimes seemingly minor things which influence movement.

### ***Unpredictable movement***

A recurring similarity through most interviews is deep concern with regard to movement, most notably associated with the unpredictability of environments and situations which may arise in the act of moving. Not only did respondents suggest wariness of unknown environments, but also of change, imposed from the outside and impacting on learning disabled lives and structures. Moreover, many people with learning disabilities were concerned about how the movement of others may negatively influence them while moving, with some understandably constructing fears from past experiences in which they have come to harm. The thought of movement has, for many, become worse than the act itself, its very conception bringing with it 'disabling' fears which limit movement outside of the home.

### ***Concern and the movement of others***

For some, these apprehensions regarding movement are so severe that they begin to impact negatively on their mental health, in turn influencing their ability, both mentally and physically, to move around their daily lives in certain and specific ways. Claire (51) talks about

visiting her family who live further away from her home than she is comfortable travelling:

*That's quite a bit away for me, I'm alright if I'm going in a taxi but if I've got to go on the bus. I'm no alright to go myself, it's too ... I used to be able to do that but ... I just don't do it any more unless I get a taxi or someone comes to pick me up.*

*(Claire, 51)*

It is clear that Claire feel that she *must* make this journey despite the fear over her lack of control which she experiences when she leaves the supposed safety of her home. It is also interesting to note that how she travels between point A and point B matters greatly to how she feels about the journey itself. If she is able to take a taxi or be driven, this form of movement seems somehow less challenging; a drop in her fear levels directly correlating to the number of outside actors likely to interact within her journey. This fear, then, is derived from previous experiences in these specific spaces; for Claire, it derives from once being badly attacked when walking home, an attack which resulted in a need for facial reconstruction.

#### *Experiencing spaces with movement*

Within the research, Claire is unfortunately not alone in experiencing negative happenings while moving around her environments, for others report similar incidents affecting how they feel about repeating journeys through the same, or similar, environments to ones where they had prior negative experiences. Both Aimee and Mae (50) describe unprompted attacks:

*A guy approached me, just outside [her home]. I was trying to get away, he kept grabbing me, so I came straight [home] and phoned my dad [...] my mum phoned the police and they came up and then CID came up and took all my stuff away so I'm going to*

*court next year*<sup>76</sup>.

(Aimee, 29)

*See when I was coming back from somewhere [...] I came off at the train station over at the top road and I got jumped [...] It was just two wee idiots looking for money, but they never got it. I just belted them and they ran away. I had money in my pocket, but they weren't getting it [...] They just jumped on me and asked me for money, [and] I said 'I haven't got any money'.*

(Mae, 50)

In both these instances, individuals have been subject to attacks in the act of walking home: walking through spaces which were, for them, known and normal, and as such deemed safe. These acts not only knocked their confidence and self-esteem in general, but specifically had effects with regards to moving through their local environments, especially independently. For Aimee (29), this attack happened outside her own home, a space in which she had previously felt secure, and so this changed how she felt about her home-space and the surrounding area, particularly since her attacker lived locally and was known to herself and her family. Mae's attack had happened while she was carrying her white cane, an additional health need beyond her learning disability. As opposed to giving Mae more confidence and freedom in her movement, the act of carrying her cane now makes Mae feel like a more vulnerable target as she moves around the surrounding area, and so she tends to leave it at home now, negatively impacting on some experiences otherwise afforded to her with the use of the stick. Thankfully, though, not all examples of unpredictable movement are quite so extreme as these examples.

### *Disturbed routine*

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<sup>76</sup> Aimee's attacker was well known in the community and physical evidence will be used in court case.

As has been witnessed, the unpredictability of the act of moving can, with one unexpected interaction, disturb set routines with which many PWLD are comfortable and secure. When these movement routines become disrupted, the consequences for confidence and mobility can be felt keenly. While leaving a writing club which she regularly attends, Barbara (48) was subjected to a stop and search by the police in relation to drugs. This interaction with the police outside a space where which she usually feels comfortable changed how she felt about attending that particular club, worried as she was that she may be subject to this aggression again. Moreover, it became a place where she felt victimised, a place where “you don’t know who’s watching you”, where previously it had been one of very few opportunities for Barbara to leave her home. For many weeks after this incident, she refused to be near the building, impacting on not only her movement but, relatedly, her sociability and education. Disturbances to routine, however, may not necessarily be an experience which is so blatantly disruptive.

For Maria (64), the movement of others can cause a disturbance to how she feels about her own home and the routines to which she, and her fellow neighbours, adhere. She explains that “the neighbour is a wee bit do do<sup>77</sup> next door and is inclined to leave the snib<sup>78</sup> up”. By forgetting to lock the main door into the building, the neighbour unwittingly causes distress to Maria’s set routines, one which makes her feel safe and secure. As such, Maria feels unable to participate in her normal movements unless she can be sure that the door has been properly locked.

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<sup>77</sup> ‘do do’ meaning forgetful

<sup>78</sup> The snib on the shared external door, preventing it from being opened from the outside.

What these examples also highlight appears to be a gendered issue with feeling safe<sup>79</sup>. Those who report feeling particularly unsafe or having been physically attacked were all female respondents with learning disability. It is fair to say that these women felt more vulnerable than their male learning disabled counterparts, in part because of the negative experiences encountered while moving through their lives. They report feeling more 'at risk' of verbal and physical violence than do learning disabled men, who, within this study at least, largely brushed aside or undersold their experiences of negativity of any kind; like Darren's "that's just what happens" attitude to bullying. This gendered mobility is a pressing issue which cannot and should not be undervalued in understanding how those with learning disabilities interact with the communities and environments in which they live.

### ***Just 'getting out'***

Many respondents, often despite negative experiences such as those noted above, describe movement as a form of their self-expression and, as such, make it ever more important to understand those things which both help and hinder movement in and around the community. Those interviewed express delight in, as Wilma (23) put it, 'just getting out' of the home-space, even for a few hours. The practice of movement opened the possibility of new and exciting experiences, most importantly breaking free from the structure and monotony too often the norm at home, providing those with learning disabilities with a chance to socialise on their own terms and so becoming visible.

### ***Movement and the social***

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<sup>79</sup> The gendered experience of fear is widely discussed by Pain (1997) and Valentine (1989; 1992).

The types of movements regularly spoken of were those which took place away from the home or family unit, entailing encounters with and around those with and without learning disabilities. Movement as a social act is linked closely to feelings of independence for those with learning disabilities; and, when asked about what makes her feel independent, Kim (47) answered, “I get out a lot”. Being out alone, acting autonomously and without any type of supervision (from parents or carers) allows many of those interviewed to feel empowered as self-sufficient adults. This is particularly important for a population who are regularly equated with, or treated as, children, and was a specific source of pride for older respondents. Many older participants had previously experienced a very different social and cultural discourse regarding living as a learning disabled person; one which favoured collective incarceration alongside others with a range of learning disabilities and mental illnesses, in hospitals and units specifically designed to keep them separate from the ‘normal’ population.

Darren’s experience of having a car enhances his feelings of independence:

*[I]t gives you quite a lot of freedom; you can go over to see Mum whenever you want, you can go places whenever you want, but, saying that, we’ve got a good bus service out where we are<sup>80</sup> as well so it doesn’t really matter, the bus service is just as good. But it’s easier to get to Mum and Dad’s if you’ve got the car and that’s the only difference.*

*(Darren)*

Owning his own car not only allows Darren freedom geographically, but also temporally and socially, since he is able to decide when he goes, who he visits and for how long, without thinking about bus times or changing carer shifts.

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<sup>80</sup> Darren lives in a small rural town, as discussed previously

Movement can also be considered a relationship building process, allowing those with learning disabilities the opportunity to make and to maintain friendships:

*I said [to friends] what we will do is we will go over [to Dunoon] one Saturday [...] The bus goes on the ferry and it doesn't cost you anything. Morag has a bus pass and so do I [...] so we went for a wee walk and there's a wee place called The Rock and the two of us went in for something to eat[.]*

*(Mae, 50)*

Free and easy travel to nearby towns and cities allows Mae to interact with her friends in a way that is meaningful and fulfilling, providing not only new experiences, but building memories and close ties to those with whom she travels. For Mae, these trips represent her independence and, more importantly for her, maintain a positive self-esteem based on her abilities as opposed to her learning disabilities. These opportunities for friendship and gratification are central to the concerns of Robert's father about proposed changes to the award of independence payments, which he feels would hinder his son's movement if the family could no longer afford to pay for day services:

*[I'll use] an example of a woman, she was older than me, she was sitting in her chair and her daughter thought [independent payment] was a great idea, you know, so I pointed out to them and said 'yeh that's all she wants to do, just sit in front of the TV, that's fair enough'. I said, 'but what about people [...] that are young and they go to the day centre?' That's where their life is, that's their friends, boyfriends, girlfriends, that's their social life, I'm not going to rip it away from them you know?*

*(Robert's father)*

In Robert's father's opinion, the idea of a more sedentary lifestyle offers little in the way of social growth, condemning some with learning disability to a life in which social circles are reduced to those

family, friends and carers who are able to visit at home. It is therefore important socially, and for the mental health of those with learning disabilities, that they enjoy all the positives that can be experienced when moving and interacting within the communities in which they live, even if this is only with others with learning disabilities. Although it does not sit easily within a radical social inclusion agenda, which calls for full non-learning disabled/disabled integration, even social interaction with others with learning disabilities is, nonetheless, crucial to everyday wellbeing and belonging.

Scott (20) discussed how his movements, particularly within his theatre group, allow him to socialise in a way which he finds cathartic:

*It's quite fun when you sit at the circle and do some of the acting. You're a good baddy or a bad baddy and pretend you're raging, or a good good guy like that 'oh I want to come to the disco with you' like that, and then some are acting, like when you're mad and angry and raging, like 'who did that to my garden?' like that, that's kind of fun though like that.*

(Scott, 20)

Acting out emotions such as sadness, happiness or anger in a safe and supportive environment, surrounded by friends, allows Scott (20) to explore feelings which he finds difficult to discuss in any other context. By literally moving through these emotions, Scott (20) has been learning how to control his reactions outwith the theatre space, enriching his relationships with family and friends, and giving him the confidence to 'get out', to meet new people and to try new things. Getting out of the home more often can also bring with it a sense of purpose, as described by Grant (29), who regularly walks his next door neighbour's dog. Not only does he feel that he has been given a position of trust, but in the act of walking he has the opportunity to experience and to explore his surroundings on a regular basis, becoming a familiar face. For some, this lack of regularity of

experience outside the home can become problematic, with Carol's mother describing how Carol (29) is unable to partake in a 'proper job the way everyone does' due to the unavailability of suitable positions for PWLD. Hindering this ability to 'just get out' therefore brings frustration, potentially impacting more widely on social visibility, a prevalent theme throughout the interviews and one explored in Box 4.

#### **Box 4: Case Study with Lawrence**

Lawrence too discussed the ways in which participation in learning disabled specific groups enhanced and encouraged his movements in a number of ways. In particular, he cited Inform Theatre Group (shown below and included within Lawrence's photo diary) as one of the main routes through which he could experience movement to venues and meetings beyond his immediate home, impacting on his life in various ways.



Within this small-scale community, Lawrence explains "I get to meet people and I enjoy being with these people. It makes me feel good", a clear indication of the ways in which movement can be uplifting and emotive. More widely, he discusses how he "gets out more because of the Rep" (a shortened name for Dundee Repertory Theatre) and that, while in attendance, they "help me with my exercises", aimed at improving his stability and walking. The act of just

getting out is one already tackled within this thesis, further highlighting the importance of such opportunities for learning disabled movement, a group who may otherwise lead a more sedentary life. The act of performance itself is enjoyable and Lawrence recognises that his confidence has grown as a result of his participation in this drama group. Moreover, he also stresses that through participation in classes, Inform “help me to remember to do things”, drawing links between mental health and movement. The chances afforded by mobility further validate the importance of learning disabled social spaces in which the supportive and encouraging potential of other learning disabled group members and non-learning disability group organisers has larger-scale ramifications for physical and mental health.

### *Visibility and movement*

In ‘getting out’, like Grant (29) and his dog-walking, many respondents describe a process of becoming seen and recognised in their communities in a positive way, making them feel like active and participating members. Darren (42) discusses his experience of life in his small town on the outskirts of Glasgow:

*It’s a village! If you know a village, you don’t just sit around in the village, they won’t let you sit around, there’s always something on that you can go to and you can pick up off the board as well what you want to do. You can go to the library and pick at the library<sup>81</sup>. If you want to do something, you just contact the person or you see the person. You might see them in the shopping centre and you can say ‘oh is it OK if I come along?’ That’s how I got in to music. I just saw the guy in the shopping centre [...]. Everyone will say ‘hello’, ‘how are you?’ and that kind of thing. It’s a very nice village, very nice. Nothing very much happens, but you talk to each other and you see each other, tell each other things, you can leave your door open at night times. There’s not many places you can do that in.*

*(Darren)*

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<sup>81</sup> The noticeboard at the library where all local goings-on are advertised.

Rather than feeling oppressed by the constant gaze of the “rural panopticon” (Philo *et al*, 2016:2), for Darren, having people around him who regularly interact in his life in the most mundane of ways allows him to feel that his learning disability does not matter. These are welcoming community spaces which are free from the stigma experienced elsewhere. Mae’s (50) own visibility came as something of a surprise, when fellow travellers on her regular bus journeys began to notice how she was feeling, noting, “they can tell when I’m alright and tell when I’m not well”. Through regular movement, Mae found herself in regular contact with familiar people, so rendering her more visible within the community. Exchanges regarding her health nurture a caring environment in which she feels less alone, an emotion which Mae is prone to feeling as she suffers from bouts of hearing and sight loss, so experiencing extreme disconnection from those spaces around her.

Crucially for Mike (29), becoming more, or less, visible and engaged in the community has become a marker by which he can measure his own level of mental health and, thereby, his own stability. He explains that, when stable and happy, he is “out more, working and out, getting company at night and meeting different people”, and in this way embedding himself within useful community networks which work to maintain his mental health. Previously, Mike states, “I was just in the house, I was locking myself in and I wasn’t going out because I wasn’t wanting to get back in to all the drinking”. The problematic social networks in which Mike was moving at that time, discussed earlier, exemplified all that he felt was wrong with his life. Since becoming more active in his local groups, however, Mike has constructed support networks that recognise when he needs a little more help and so encourage him to be more, rather than less, active in order to resist temptation. Through these groups, he has also begun to help others with learning disabilities who struggle with depression and substance

abuse, passing on his knowledge and becoming a role model for others on the same journey, a role in which he takes pride.

It is clear that the act of 'just getting out', like Allan's (32) walks in the park, pictured below (Figure. 19), has various benefits to those for whom movement plays an elemental role. Through movement, those with learning disabilities grow in confidence and ability, becoming not only more self-sufficient, but more assured in their control over their own lives, even in small ways. By moving from



**Figure 19.** Showing Allan taking a walk in the park near to his home, an image he flagged as important from his photo diary.

Space to space, those with learning disabilities can become more normalised within mundane community environments, so perhaps achieving the inclusion so highly regarded in the process of deinstitutionalisation. What is more important here than total inclusion, though, is to look at the networks through which those with learning disabilities move, some joining groups and clubs and sharing friendships with those without learning disabilities, but others enmeshed within care structures and spaces for those with learning disabilities. It could be argued that community inclusion for PWLD comes not from complete involvement with all members of the

community in which they live, but rather in having the freedom and independence to move within and between those smaller communities which are important to them, building networks in which they feel fulfilled and happy. Essentially, the main concern is not to force integration of PWLD at every level, but rather to open channels of accessible movement which empower those with learning disabilities to carve out their own identities, however they may be constructed.

### ***Movement of and at home***

Central to this thesis, and a key focus of this chapter, is the notion of the 'residential landscape' through which we can begin to know the changing spaces which those with learning disabilities have called home. The move away from institutional living, which began in earnest in Scotland with the *SAY?* (2000) policy framework, created new opportunities for residential discovery; a notion as potentially terrifying for PWLD as it was exciting. On the surface, the statistics release from SCLD (2015) states that 78.4% (21 324 PWLD) live outside an institutional setting<sup>82</sup>, but what is lesser known are the experiences of those PWLD as they negotiated their way out of the institution. Moreover, for those PWLD who have never lived within an institutional settings, these figures serve further to mask the structural and personal limitations, possibilities and negotiations involved in finding a space to call home. Movement of home from one location to another is a potentially unsettling experience wherein PWLD are removed from familiar environments and established networks, sometimes without their consultation. Though initially frightening, some moves can become empowering, particularly where

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<sup>82</sup> 78.4% speaks to those PWLD in mainstream and supported accommodation, with 7.4% in adult care homes and 14.2% as unidentified 'Other' accommodation and 'not recorded' (SCLD, 2015).

decision-making, control and movement go hand-in-hand. It is important to consider movement from place to place, then, but also the smaller scale realities of movement within the home-space; movements which were difficult to discuss and rarely offered as topics of conversation.

### *Moving home*

Although stressful for most, movement of home for PWLD can be a catalyst for much larger, social changes, often also meaning a change of carers, day centres and groups, as well as the expected changes in surroundings and environment. The level of change experienced can therefore impact greatly on how PWLD then feel about the home-spaces in which they live, particularly when the choice to move has been made on their behalf. John (55) discusses how the death of mother resulted in his father deciding to move him to a care home where he felt he would be better cared for. This movement to a new home environment, away from the family unit, resulted in John feeling confused and “a wee bit sad [...] because I can’t see Dad”. After the death of his mother, losing his father and familiar surroundings was initially difficult for John to come to terms with, and he continued to feel unsafe in his new home, moving to a new facility shortly after.

For others, the process of moving was one which, although at first intimidating, offered a sense of empowerment, a chance to re-invigorate surroundings and to make them ‘their’ own. Darren (42) states, “you can do whatever you want in your own house. You can sit and relax in your house and you can also see lots of places, you’re not in quite a lot as everybody knows!”. In moving house, Darren found that new experiences, both at home and outwith, were available to him, opportunities which had not presented themselves when living with his mother. By moving house, Darren also discovered more

movement outside of the home, his flat becoming a solid point of reference from which he has been able to explore locally and socially, so finding out more about who he is and what he likes through movement.

Making plans to move can also be empowering when PWLD find themselves able to do so:

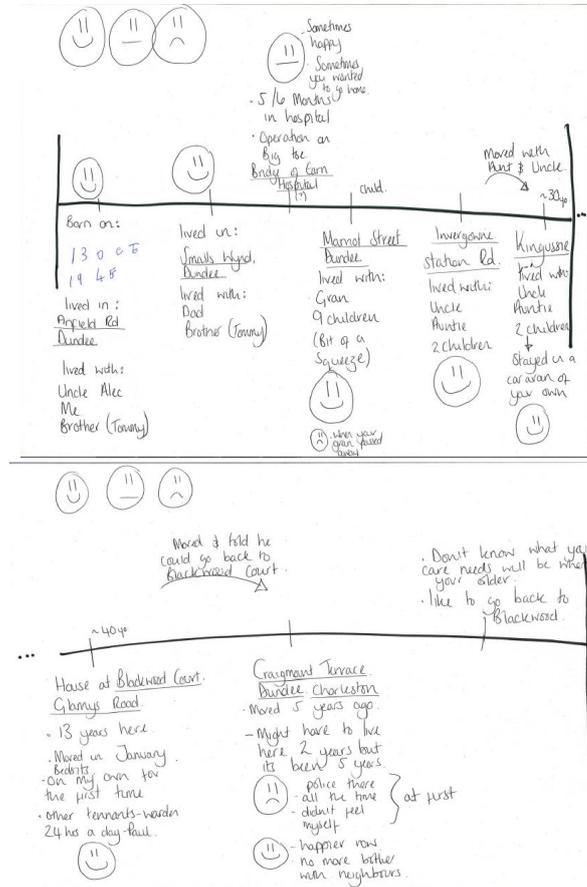
*I want a wee bit of space away a wee bit. My sister stays [close by...], I take care of her and I feel, I just feel that's where I want to go, back my own end. There's been a lot of rough [people] up here for the last couple of months [...] Susan [his family friend] says to me 'aw you're fine' and I am fine, but I feel I want a wee change out of here and try and move on.*

*(Mike,29)*

For Mike, the chance of movement to a new home in the neighbourhood in which he grew up, his “own end” of town, is a chance for new beginnings, a way of leaving behind some of the mental health issues that he has faced living within his current home. His description of local people in his current neighbourhood as “rough”, mirrors his own ‘rough mental state’ within those affective spaces, adding yet more weight to the importance of location in the mental and physical wellbeing of PWLD. Moreover, this anticipated fresh start is in a place with which he is already familiar, where he is close to family and knows the people and places in the community. Moving home in this instance would be a positive step forward, representing a change in how Mike feels about his life now and his intentions for the future. This is a move which is not merely aspirational for Mike, but achievable. It is not a move, however, which

is necessarily supported by his carer, signalling potential difficult negotiations and decisions in his near future.

**Box 5: Case study with Lawrence**



One of the first tasks Lawrence and I undertook together was to create a timeline of the places in which he had lived, creating a linear map of his residential landscapes (seen large-scale in appendix 11. What is clear from this map, and perhaps surprising, is the number of places which Lawrence has called home throughout his life. These places, as indicated by 'happy', 'sad' and 'indifferent' faces, were mainly positive home spaces in which he resided with his family before moving into a home of his own at around 40 years of age. There are some unknowns also highlighted by this timeline, like why Lawrence never stayed with mother, seemingly only staying with his father for a very short time as a child. The reasons for this remain a mystery to Lawrence as well as to myself, perhaps indicative of a time, the late 40s and early 50s, when parents and elders did not discuss matters such as this with their children or, indeed, a reflection of his perceived ability to process such information. Whatever the reason, Lawrence's grandmother became his main carer until she died. Despite describing life at his grandmothers as "a bit of a squeeze" (there were nine children in total,) he recalls being happy and supported within a close family unit.

For a short time, around six months, Lawrence also spent time in a residential hospital facility, during which time he had an operation on his foot in order to help him walk more freely. He recalls being “lonely and sad”, his family unable to visit regularly given the distance between Bridge of Earn and Dundee on public transport. Being cut off from his family in this way reduced his mobility even in the act of medical intervention attempting to improve his range of motions. Upon the death of his grandmother, Lawrence once again found himself moving home, living with his aunt, uncle and their children, giving no indication that this move was discussed him, let alone suggested by him. It would seem that, in ensuring that Lawrence stayed within the protective unit of the family and out of the potentially more permanent institution, he resided with those people who had room to accommodate him at that time. Although he enjoyed living with his Aunt and Uncle, his time with them involved two moves, one to Invergowrie and one to Kingussie, with the rural nature of these locations precluded opportunities for movement as a person with walking difficulties, closing down spaces in which he was able to create a sense of belonging.. Not only did Lawrence once again have no input, simply moving with the family, but Lawrence continues to describe himself as ‘happy’ in most of the residential situations in which he has found himself (Charleston aside), but it was not until his discussions with his brother, Tommy, led him to Blackwood Court, and into a home of his own, that Lawrence began to explore those movements available to him outwith and within the home-space which offered him opportunities for belonging and inclusion. This personal growth makes it all the more difficult to come to terms with the manner in which he was removed from Blackwood Court, a further residential move over which he had no control and which offered very few viable options, if indeed Lawrence fully understood what his other options may entail (see Box 1). Moreover, this is not the story of choice and control over residential mobilities that would be expected post *SAY?* and *TKTL*, indicating that there is still a gulf between political frameworks and the lived experiences of PWLD. His time in Blackwood Court instilled in Lawrence a quiet confidence which has been reflected in the active movements that he has made to maintain his old ties in his old community, further providing evidence that opportunities for autonomous movement breed confident and mobile learning disabled individuals.

### *Moving and movement*

Moving to a new home environment for a fresh start can be at the same time positive and negative, as experienced by Eilidh (29). Although her new home-space was one which was positive for the family, it changed other daily movements which were previously available to Eilidh outside of the home and further adding weight to

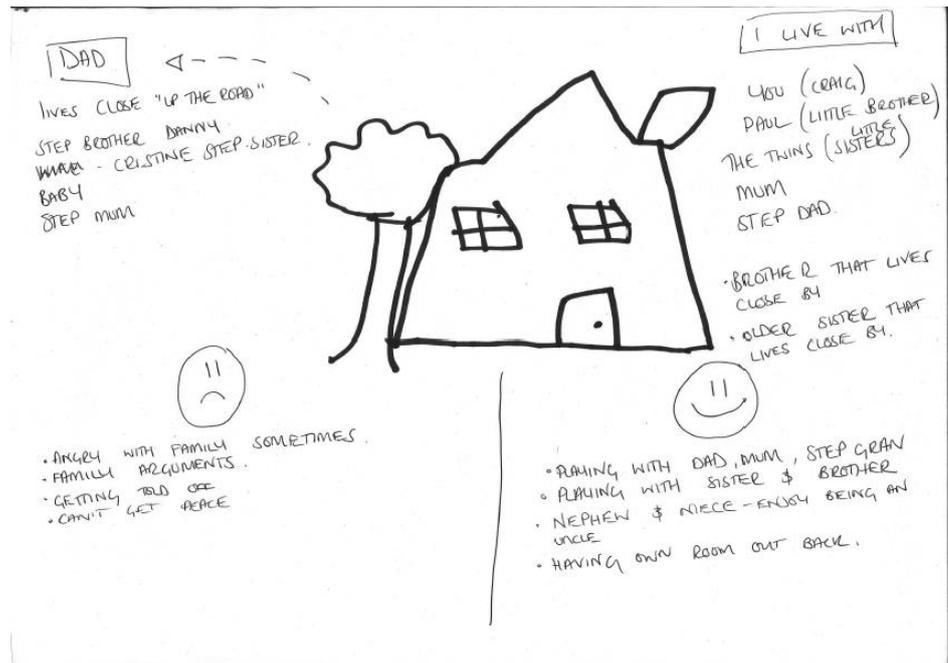
arguments by Power (2013; 2016), among others, that where one lives impacts on the opportunities locally available:

*When we stayed down Harwood [Street] she would go on the bus and I would take her up to the bus, put her on it and it would take her to almost the college and she was able to walk up and cross over, but that's because that was familiar [...] There was a bus actually [...] and it used to come up [...] along here. I didn't know that when I moved here [to the new house] but it came along there, only in the morning though. And she used to get picked up out there and get dropped off at the college.*

*(Eilidh's mother)*

In her previous home, Eilidh had been provided with more opportunities for independent movement, something that was not available when she moved home. The new bus route was soon cancelled, and so it was decided that Eilidh's father would take her to college instead. Although living within the same town as she had been previously, moving to a new part of the town made considerable changes to the ways in which Eilidh then travelled between the places that she regularly visited. Moreover, Eilidh and her mother discussed how previously they had taken walks around their home which were no longer available to them, further reducing Eilidh's experiences around the spaces and environments in which she lives.

Where parents and/or family members no longer live within the same household, some respondents found their home lives to be more mobile than others, as they found themselves split between two, or more, different home spaces. Darren (42) describes visits with his father as "the less said the better", rejecting his father's home as any extension of himself or his family, but for other respondents the idea of 'home' became much more fluid and diverse. When initially asked to draw his home, Scott (20) was unsure which to pick; seeing



**Figure 20.** showing an extract of Scott's home map

himself as simultaneously represented by two home-spaces, and so he asked that we describe one home on the right side of the page and the other on the left, indicated by MUM and DAD (and the two small boxes in the upper corners) in his drawing. Moving home is, for Scott (20), a regular occurrence as he moves weekly between two family units of which he is a part, each representing a space in which he has different roles to fulfil. As the eldest sibling still living at home within each family unit, Scott very much finds himself existing between two families, yet, due to financial reasons exacerbated by his inability to find suitable employment, he is unable to move into a home of his own as his older siblings have done upon reaching his age. Instead, Scott has moved into a small annex in the back garden of his mother's house; a separate space which recognises his need for a place of his own but allows him to remain close to family support structures. Scott's experience of 'moving' home are entirely personal and in no way the moving trajectory of all PWLD, but it stands to show that there are many version of 'home' which suit the needs of PWLD, both as adults seeking to lay down their own boundaries, and as adults who

need care and support in various ways. With his father living “just up the road” and his annex “just out the back”, Scott’s moving landscapes are, geographically speaking, small-scale, but they represent alternative home-spaces in which PWLD can be offered a certain level of independence, control and decision-making capacity.

### *Moving at home*

Those, often private, interactions which take place in the home-space are difficult to discuss normalities which are often taken-for-granted movements, but are nonetheless important for understanding how PWLD feel about their homes. While home is for some a space of safety, it may also be a space which can become worrisome, often for the most mundane of reasons:

*My hands are bad at times. I couldn't get my window open, neither I could, and I panicked and, oh I really mean it [beats hand on chest], I panicked and I used my mobile to phone over to the concierge and asked if somebody could come up and give me a wee bit of a hand [...] and the concierge came up straight away and they managed to get the window open and that reassured me.*

*(Claire, 51)*

Normally, her home is the space in which Claire is able to feel safe, and, importantly, a space over which she has full control, including over who she interacts with and when. On occasions such as those described above, however, Claire’s perceived loss of control changes her relationship with her home, leaving her unsure and panicked. Despite her normal feelings of contentedness at living alone, this particular incident left her feeling unsafe and unsettled, highlighting the importance of finding suitable homes for PWLD. The act of inviting a person unknown, the concierge, into her home-space is clearly indicative of the panic induced by a seemingly trivial incident. Indeed, in order to speak with Claire myself, we held several phone

conversations to prepare her for my arrival and I was forewarned that, on the day, I may well be turned away if she did not feel comfortable having me in her home. Asking for help with her window on this day was no small feat for Claire. Although she does not require 24-hour care, nor panic alarms or housing adaptations which would be available in a sheltered housing complex, it is clear that Claire does need to be supported at home, if more mentally than physically. As such, it is crucial that PWLD are recognised as more than 'just' learning disabled to ensure that their homes support and encourage positive physical and mental health. While happy to live at home, Claire's experiences have shown that, for some PWLD, it will always be important to have someone close at hand who can offer help where needed.

Feeling a loss of control in the home-space can be particularly upsetting for PWLD, often most keenly felt by those who are less able to make decisions which could change their situation; an issue discussed at length in Chapter 4. For John, his initial stay in a residential home for PWLD and the elderly allowed, for him, too much movement of others through spaces which he felt should be more private: "Sometimes a lot of people in my rooms". In particular, John felt uncomfortable having so many people around him when he was eating, stating "sometimes it was a wee bit bad". Again, this is a seemingly small and easily remedied spatial problem, but one which for him made a notable difference to his overall happiness. The movement of others in what should be private spaces can be difficult to manage, since many PLWD do not have the language to express concerns nor to resolve conflict. This issue is entwined within arguments made in Chapter 5 about PWLD not always having the required 'tools' to mediate decisions within and about their homes. As in John's case, moving home becomes the primary mode of conflict resolution, bringing with it further concerns related to learning about

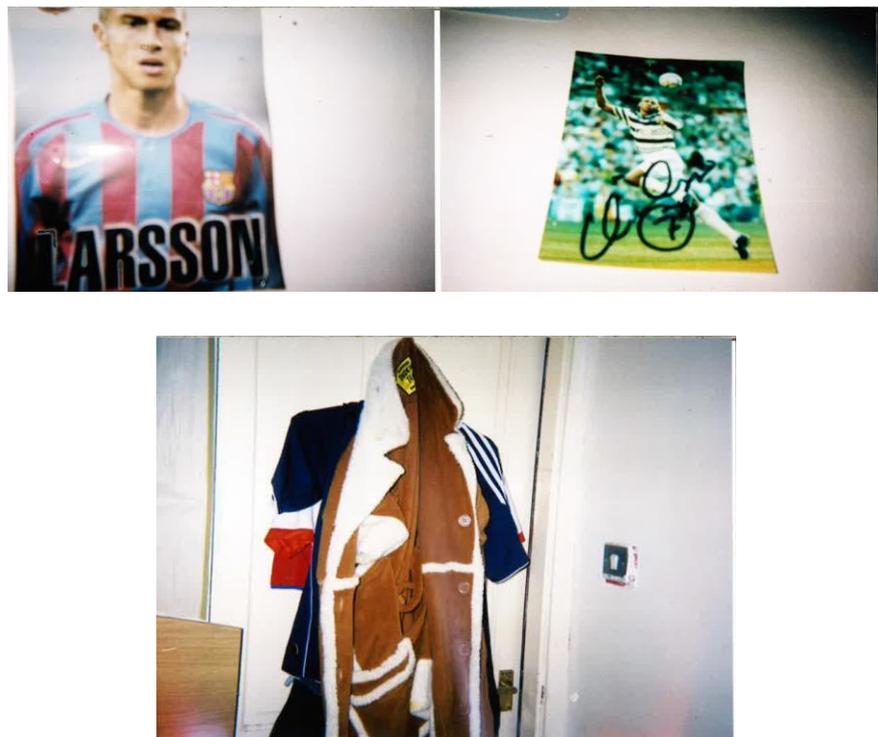
new areas and accessing required services. Moving home in these cases may simply resolve one set of issues while simultaneously creating new ones, as embodied in the complications of Lynne's previously mentioned move to a care home facility.

Throughout the research, it became apparent that those who live in their own home experience an increased potential for movement within their home-spaces, as compared to those who live with their parents or with others with learning disabilities. PWLD living within their family homes may, in fact, experience similar internal boundaries which Sibley (1995) aligns with children and young adult living with their families. Living within the family home hence involves the same parent-defined limits and boundaries which must be negotiated and navigated. This boundary-setting is not an inherently learning disabled issue, despite the increased likelihood that PWLD will be infantilised by their parents and others; rather, it is an issue entangled within ownership of the home-space and rights to define certain areas as one's own. Both Darren and Kim (47) speak about spaces within their own homes which they like to inhabit, ones to which they previously did not have access when living with their families. For Kim, the opportunity to move around the kitchen freely, to try out new recipes and to cook meals for herself, opened up a new and exciting hobby and a keenly felt sense of purpose. It not only allowed her to feel more independent at home, but also led to a job in the kitchen of a local café, so opening up Kim's social worlds yet further and positively impacting on her opportunities for interaction with others. Darren too enjoys more freedom of movement around his home and, in particular, appreciates having his own shed which "no one is allowed in but me". As a keen gardener, he feels that this extension of his home-space allows him to feel 'at home' in another space. Moreover, even though this space is a solitary one, it allows Darren to have time away from the normal movements of home, to think about his life,

allowing him to have a better handle on his mental health. In this space Darren can have full control; control over who enters and control over his feelings and mental health when in that place. Although, by his own admission, he can be “just as happy” in his house as in his shed, it is a space which he vehemently defends as his, and only his, laying out boundaries which he defines solely as a space for Darren, into which no one else is invited (Sibley, 1995).

Alternatively, those who live at home with their parents seem to lead more sedentary home lives, revolving around smaller, more defined spaces. Both Carol (29) and Wilma (23) spend a lot of time in their own rooms and surrounded by those things which are important to them; Wilma describing her room as “probably her favourite place” in the house. These spaces afford the possibility to be alone, to listen to music, to watch TV, and to go on the computer without disturbing or being disturbed by others. As young adults, these young women with learning disabilities still find themselves within a “transitional phase” which is only said to be complete “when children enter adulthood” (Wyness, 2000:24). For PWLD, this is a highly problematic limbo, since those with learning disabilities are often deemed to be in a perpetual state of childhood and, moreover, cannot easily access those arenas which signify adulthood; chiefly employment and home ownership. By outlining and maintaining spatial boundaries within this infantilising discourse, Valentine’s (1996; 1999) argument that use of space is a constant parental battle is turned on its head. The spatial “headache” (Jenks, 2005) is instead battled by young adults who have long since ceased to be children and, in the case of many PWLD, are, for many of the reasons already discussed in this thesis, unable to set up home on their own. Their control of movement within at least one room of the parental house offers at least some opportunity for self-expression not always available when living in someone else’s house.

Matthews *et al* (1998) argue that the young adult's room is an important place of solitude, as echoed by Wilma (23) and Carol (29) above, but it is also a space in which personalities can be expressed and explored. Although Carol uses her room as place to 'escape' her family ties, it is also a space in which she can showcase a little of herself. Carol's mother describes her vast collection of Disney videos and DVDs, collected by, and gifted to, Carol throughout the years. This collection is highly prized by Carol and her mother warns that "no one else is allowed to touch it", a clear spatial boundary over which Carol makes her ownership very clear. Attempting to showcase personality can be further problematised by the need to share bedrooms with siblings.



**Figure 21.** Personal items from Matt's room, which he shares with his brother.

Although Matt (23) admits that the footballing images shown top right and left of Figure 21 were partly to tease me as a supporter of a rival club, these images also serve to display some of the ways in which he

has sought to make his space reflect a little more of his own personality, expressing his pride in owning memorabilia signed by his favourite player. The 'Del Boy Trotter' house coat, also pictured, was not only an important way that Matt demarcated his belongings from his brother – “this is my [door] hook” – it is also signified his deeper feelings within his bedroom; in this space, and wearing this particular item of clothing, Matt could feel relaxed, safe and comfortable in his surroundings.

### ***Making moving-landscapes***

As Sheller and Urry (2006) note, “many different bodies are on the move” and, as such, mobility is not merely a means of accessing different localities, but a “constitutive framework ..., providing opportunities and constraints, freedom and limitation, justice and inequality ... over time and across space (Shaw and Hesse, 2009:306). As has been evidenced throughout this chapter, for PWLD, lack of movement impacts on the chance to meet new people, go to new places, discover new things about oneself and, importantly, realise ambitions. Ahmed (2004:152) contends that mobility can only exist in opposition to others who are “not free in the same way”, but Sheller and Urry (2006) recognise a new mobilities paradigm which pushes beyond such binary framings and begins to focus on how power is contextually produced to create a raft of different possibilities for movement and stasis. If, as Sheller and Urry (2006) claim, travel is necessary for social life, it is essential to think about mobility not just as a means of travel, but as social, cultural and politically motivated modes of individual movement and stasis of all kinds, including movement of and at home. Without appropriate and fulfilling mobility, many PWLD are left without the skills to track their own way through life: to make decisions regarding movement, be that moving home or simply catching the bus. The more one moves, the more one can move, or indeed not, but the ability to make a conscious choice,

is essential. The possibility for movement and the act of moving itself are central to the happiness and overall quality of life of learning disabled individuals. Those interviewed perfectly display the personal achievements, both small and large-scale, which can be experienced should the 'risk' of movement be undertaken. These, often small, pockets of possibility hold within them visions of a future in which many more PWLD feel empowered to control how their lives are lived. Movement at a number of scales, independent or otherwise, undoubtedly breeds confidence: confidence not only in the ability of those with learning disabilities to make moves when they wish, but also confidence in their ability to make and enact decisions and changes which they feel would result in more positive life experiences.

Much like in other areas of learning disabled lives, budget cuts, with the resulting changes in how money is distributed and made available, affect how and why PWLD move around their local environments (as discussed in Chapter 3 and evidenced within this chapter). Personalisation agendas have, rather than empowering and enriching learning disabled lives, arguably begun to shrink the social worlds inhabited by PWLD by reducing availability and choice (see Hall, 2011; Power 2013; Power *et al* 2016). *TKTL* (2012) has suggested that these gaps in provision can be met simply by providing more funding to advice-giving services, such as citizens advice. In reality, a lack of movement opportunity, and therefore limited confidence in the act of moving, constricts the likelihood of a person with learning disabilities seeking out and obtaining help. The very act of 'seeking out' in itself requires movement, especially since many PWLD may find it difficult to engage with phone-based and online consultation. Under the cover of improving services for PWLD, this shift in budgeting greatly impacts on outcomes for those with learning disabilities, not necessarily in a positive way.

Budget cuts further restrict how PWLD think about and rationalise their movements, or lack thereof. With major cuts against college classes (discussed by both Barbara (48) and Grant (29)), support groups (mentioned by Mae) and services (evidenced both by Paul and by Nicola and Rebecca's experiences), some PWLD become limited in their ability to imagine more for themselves. For those mentioned, and others, limited resources and reduction in class hours were just 'one of those things'. Continued lack of movement has become, to some extent, an expected outcome of living with learning disabilities and, certainly for those taking part in this research, there appears to be very little in the way of self-advocacy. It is a worrying prospect to conclude that some PWLD are so restricted in their movements as to regress to an institutional state of acceptance with their lot in life. Parents interviewed also spoke acceptingly, if not despairingly, about their current 'state of affairs', being resigned to how, under current austerity in the UK, these outcomes are the best that can be hoped for. Movement, then, is not only an act of getting from one geographical location to another, but an indication of the corporeal impacts of policy implementation and continued budget cuts across all areas of learning disabled lives.

Housing and care options further impact on movement of those with learning disabilities and, all too often, 'care in the community' comes at a cost to the social experiences which are then available, since care provision and approaches are not evenly distributed across localities. Scheduled and regulated movement within institutional settings has, it seems, permeated into the home lives of those with learning disabilities living outwith institutional settings. For most interviewees, this form of movement provides much needed daily routines, but a socio-medico focus remains on *adequate provision* of care often at the expense of social lives and daily movements. The neoliberalist approach to care, Lawson (2007) argues, pushes care further into the

private home-space and recasts care receivers as 'customers' and 'clients' in a market of care<sup>83</sup>. While many PWLD do experience more movement outside of the home-space than they (or their forebears) did within institutional settings, the experiences of some interviewees suggest an 'any home will do' attitude. This attitude disregards the positive physical and mental wellbeing attributed to the ease with which the surrounding environment can be socialised and navigated. While it is clear that more PWLD have their own home and social routines than they were previously afforded, there is very little to suggest that these houses provide the home comforts expected. Indeed, a lack of available and suitable housing for the varied and subjective needs of those with learning disabilities impacts greatly on their residential mobility. It may once have been enough only to provide PWLD with their own home, one which was not within institutional settings, but this focus has arguably led to a different kind of 'institutionalised' care which does not seem to progress in line with the wider needs of those with learning disabilities as they strive to lead increasingly abnormally normal lives.

For many respondents, particularly those under 30 years old, there seems to be very little emphasis on activities which take place at night. Despite a few learning disabled specific clubs running 'after dark', respondents spoke of feeling most isolated and bored by their lack of mobility *after* their routine day-time visits to day-centres, clubs or jobs. Much of the focus around mobile and interacting learning disabled community members centres on day-time activities which mimic regular, 'normal' working hours, with less attention paid to those times of the day routinely given over (by others) to socialising. Many respondents therefore rely on family member or carers in order safely to navigate their night-time lives. The alternative is to stay at

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<sup>83</sup> For a more comprehensive critique of care provision see, Conradson (2003), Lawson (2007), Miligan (2014).

home. Lack of opportunity within certain temporalities greatly affects how PWLD feel about their homes, communities and life-prospects.

Overall, movement, mobility and the act of being in motion cannot be underestimated in what they disclose about how the lives of PWLD can be improved. Those with learning disabilities already experiencing more movement speak of lives in which they are active, have friends, go on dates, visit families, have a job and partake in hobbies. These activities are distinctly ordinary but, by under-evaluating the role of safe and easily accessible opportunities for movement, a large proportion of those with learning disabilities will continue to lead lives in which they are unfulfilled: leading lives in which the individuality of decision-making, life-control and indeed risk-taking are reserved only for those who do not have a learning disability, so closing down lives which those with learning disabilities may imagine for themselves in the future. The “barriers to being” presented within this chapter therefore has obvious effects on how PWLD experience a sense of belonging (Thomas, 1999). As such, the thesis now turn to look at belonging, attempting to understand how experiences of home and community impact on the ability of PWLD to feel that they belong.

## Chapter 7

### Belonging

In thinking about what is belonging for PWLD, this chapter begins by paying attention to those people with whom PWLD have the closest contact immediately outside of the home space; their neighbours. How these individuals impact on PWLD themselves in an important facet in how PWLD envisage themselves as belonging within community spaces, or not. Delving deeper into the meaning of community, the chapter turns to thinking through those acts undertaken by PWLD which afford them different routes into a sense of belonging. Understanding that such a sense of belonging can often be stemmed by outside influences, barriers to belonging are also discussed which tackle the debilitating effects of stigma, bullying and loneliness. Finally, home is discussed, exploring the minutiae of the home environment in order better to understand the opportunities and barriers to belonging presented in these personal spaces.

#### *Why is 'belonging' geographical?*

Mee and Wright (2009:772) argue that belonging is an inherently geographical concern since it connects “matter to place” in many different ways and in many different forms, so framing belonging as “messy, uncertain, fragile, and shifting”. Specifically, Tolia-Kelly (2008) and Blunt and Dowling (2006) connect homemaking practices and transnationalism to highlight the active practices visible in the creation and maintenance of belonging in a multi-scalar way, from home to regions to nations. For PLWD, then, it is important to think about the small-scale spaces and practices of belonging which tie them to home, or not, but also those larger-scale political practices which impact on their ability to find, create, control and maintain places in which they feel that they belong. Again, it is important to

note that these opportunities for belonging are not evenly realised across geographical boundaries. Cameron (2007) further suggests that belonging has been politically mobilised as a catch-all term for *inclusion*, which recognises affective relationships with space as a “politics of place” (Stratford, 2009:796) as opposed to framing the excluded as complicit in their own exclusion (Cameron, 2006) predicated at least in part on who is subject to *exclusion*, not seen as belonging here and now. Such a perspective, so common if unthinking in many political and popular discourses, can also play out with respect to learning disability – PWLD often being regarded as not properly belonging in many places. Conversely, progressive policy (SAY?,2000; TKTL, 2013) agendas seek to reconfigure PWLD as, after all, belonging – as properly being here, now, as ‘fellow citizens’.

More sophisticatedly, Probyn (1996:19) suggests that belonging should be seen as a fluid and ever-changing set of practices which involves the continual attachment and reattachment of “people, places, or modes of being” in a reconfiguring of people, places and shared ideas which create inclusion and exclusion, inside and outside (Parr, 2006). Interesting for this research is Parr’s (2006) discussion of Probyn’s (1996:13) approach to belonging, which explores the experience of being “within and between sets of social relations”. The emphasis here is on how people with mental health problems – but perhaps read PWLD – can themselves carve out senses and spaces of belonging for themselves, striving for inclusion on their own terms, which may or may not entail seeking attachments to places with like others. What SAY? (2000) and, later, TKTL (2012) offer is a framework of total inclusion – in which everyone is homogenised into ‘the same’, occupying the world in the same way – which is somewhat disturbed by claims from Probyn and Parr; claims that belonging for PWLD can exist in a number of different or connected learning disabled *and* non-learning disabled spaces simultaneously. Moreover, it opens up the

possibility that these spaces, geographically speaking, may lie within more institutionalised and segregated places specifically catering for learning disabled individuals. Like Mee's (2009) work on social housing and care in Newcastle, Australia, working to understand *belonging* as opposed to *social exclusion* serves better to uncover the active ways in which PWLD create and subvert notions of both belonging and inclusion.

### ***Community***

Community, and in particular community integration, has, in recent learning disability history, become accepted reasoning for a move away from institutionalised care within hospital settings, to more sporadic, personalised forms of care within 'the community' itself. This move has not meant automatic integration in the sense intended, wherein those with learning disabilities would melt seamlessly into the fabric of the community, thus erasing their disabilities or at least the social difference of their disabilities. Rather, we see a re-working of mobilities and networks through which PWLD gain a sense of belonging in spaces and places which allow them to feel fulfilled, happy, and well supported, or not. These mobilities and networks of residential movement and experience are the main objectives which this thesis aims better to understand. What, then, do these community-scapes look like which lend themselves to feeling part of something greater than the learning disabled self?

### ***Neighbours***

Neighbours were mentioned throughout the interview process as a group who live outwith the family home and outside the family circle, but nonetheless are a source of support or of tension. These are the people who live in closest proximity, outwith the home, to those interviewed, impacting on their lives in some form, either in their capacity as helpful 'others' who may, as Wilma (23) describes, become

“family friends” or simply as largely unknown but regular connections to life outside the front door. For some, the attitudes and reactions of neighbours to learning disability can set the tone for how comfortable PWLD and their families feel about where they live. Robert’s mother recalls:

*I can always remember when we moved up here. [Robert] was really a baby and the neighbour across the road invited us over and all the kids were in her garden and Robert was sitting there, well half-sitting, and the kids are like that ‘what’s the matter with him?’ and I let them know. I said ‘he’s handicapped, he can’t walk like you’ and he [one of the children] said ‘it’s OK he’s just handicapped’ and that was it, you know? [...] and they all accepted him as he was, you know, playing about and that was it, it was great.*

*(Robert’s mother)*

The easy acceptance of Robert’s condition by these children, and by the neighbours in general, provided a sense of comfort for his parents, knowing that those in closest proximity to them could be trusted to have Robert’s best interests at heart.

For others, dealings with neighbours are not as profound, but are equally as important in the maintenance of personal boundaries which create a sense of belonging through safety. Claire (51) simply states, “I’m not really interested in other people’s business or whatever, it’s not really my business, but as long as nobody bothers me, I’m not going to bother them”. Although Claire would not look to her neighbours for support, nor does she feel threatened or disturbed by them, and so this provides her with sense of security, which to her is most important. Maria (64) and Kim (47) also speak of their neighbours as providers of security although in a more direct way, both naming ‘next door’ as people who make them feel safe. When asked about her home and immediate environment, Kim says,

*K: I’ve got good neighbours around here*

*V: And you like having good neighbours?  
K: Yes I do.  
V: What's good about them?  
K: I met Jimmy, my next door neighbour.  
V: And does he look out for you?  
K: Yes he does.  
V: Is that important to you?  
K: Yes it is.*

*(Kim, 47)*

Having lived in various homes alone, Kim quotes good neighbours as an important feature of a good living environment. Although she does not rely on her neighbours for any direct support, their presence, should it be required, is enough to allow Kim to feel safe and sure of her surroundings, so allowing her to lead the life that she wishes to lead.

#### *Offering support*

Much talk surrounding neighbours was not necessarily of the ways in which they *give* help, but rather the readiness with which they *offer* support, therefore providing learning disabled individuals with a safety net, often allowing them to feel in control even in situations where they are potentially vulnerable. Maria tells me:

*The neighbours are all lovely round about and fortunately they all have cars, so I am not stuck for transport. They said 'listen, if you are stuck and your carers are not going to manage to come, just give us a buzz and we will help you with your shopping'. So they have volunteered if I am stuck, if my carers can't manage or are not available: 'please just let us know'. That's another help.*

*(Maria, 64)*

Since her parents passed away, Maria is living by herself for the first time in her life. These offers of help from those around her not only remind her that she is not alone, but provide her with a lifeline beyond her care team, should it be required. Similarly, Barbara's neighbours

are sympathetic to her needs, not only as a learning disabled individual, but also as someone who is not easily mobile:

*[...] we are the only young ones in this wee bit. It's great, they talk to us and say 'right [Barbara] we are going to the centre' or going anywhere: 'do you need anything?' They know how bad I am and I can't get out or anything, so that's how, if Alan [her husband] can't get it, they come to the door and 'right [Barbara], is Alan at work?' [...] They say 'do you want us to do something for you or go somewhere with you?'*

*(Barbara, 48)*

With her husband both working part-time and acting as full-time carer, there are occasions when Barbara's lack of mobility both limits her decision-making capacity and increases her sense of isolation. It is therefore vital to her that she has this neighbourly support should she need help or simply company when Alan is not on hand to provide for her. In both Maria's and Barbara's experience, it matters less whether these offers of help are ever brought to fruition, more that this neighbourly contact is maintained, so allowing them both a sense that they belong as visible people, cared about by those who live close-by. Crucially, these feelings may be sustained by perhaps only one other person or family member outside of the learning disabled household, and can be limited geographically to a few houses either side, but the point is that such feelings can be so sustained. These small neighbourly gestures show the importance of having strong connections with those in the immediate area, even when the help offered is not needed or even accepted.

### *Giving Support*

Often, though, neighbours do provide support that is accepted, either in place of, or as well as, that from official care companies and family members. These relationships are often under-represented in the learning disability literature, but are essential in uncovering another

texture to the network of individuals involved in maintaining learning disabled lives outwith institutional care or residential services. Many parental carers, such as William's father, spoke of how neighbours lend friendship and support when they are feeling under pressure or lonely, but it is also vital to address how the support given by neighbours to PWLD themselves can help to shape confident and independent learning disabled people within local communities.

As well as regularly helping his neighbours, Stuart (42) is also regularly helped by those who live in the flats around him, with whom he has built a close and trusting relationship:

*My neighbour helps me because of my dyslexia, with my reading and writing, and helps me how to budget, how much to spend for messages and whatever. He says 'don't spend all your money, keep money in your Post Office account' or whatever. If I get a letter from the housing or the social security, I take it down to me neighbour and he reads it.*

*(Stuart, 42)*

The close bond built between Stuart and his neighbour is evident in the personal nature of the help which he accepts. Rather than reaching out to a care service for help, Stuart is more comfortable with a person that he has known for a long time and can trust has his best interests at heart. Moreover, choosing to have his neighbour help him in this way ensures that Stuart feels no risk to his own autonomy.

Wilma has also built an important relationship with her neighbours over the many years that she has lived at home with her grandparents:

*Back when my gran was here, whenever she was, you know, needing to go to into the hospital and when she was actually ill or something like that, I would sit with them and they would actually look after me until, you know, my grampa came back and stuff.*

*(Wilma, 23)*

For Wilma, then, neighbours have, throughout her life, acted as another layer of support, friendship and care, despite the very tight family circle in which she grew up. While Wilma's grandparents would not accept help from any outside care agencies, they did accept help from those neighbours around them, again highlighting the bond of trust that (but will not necessarily always) be built between neighbours through long years of close proximity. Wilma's grandfather explains that his wife (Wilma's gran) has been deeply opposed to approaching professional services since she was herself a nurse, and so, believed that she could provide adequate care. Moreover, both grandparents thought it crucial that they look after Wilma's care needs within the family, keeping a tight bond which in some way compensated for Wilma's mother having left her. Upon the death of his wife, Wilma's grandfather adds, with some sadness, that he could no longer manage Wilma's care alone and so sought help from care agencies. In addition to her professional care-givers, neighbours have, and Wilma believes always will, provide a support structure which can be relied upon should her usual family members not be able to provide such help. However, as Wilma grows more independent and her grandfather's hearing continues to worsen, the family are hesitantly coming to terms with the fact that Wilma will need to move into her own home, removing her from the community bubble in which she currently feels supported.

#### Neighbours as the problem

It cannot be said, unfortunately, that neighbours always have a positive influence on those PWLD who live near them. These people can also be a source of discomfort, or worse, and impact greatly on how isolated those with learning disabilities feel in their homes, often changing when different people move in or out of the area. In Mike's (29) experience, the change of neighbours has positively impacted upon his living situation as it stands currently:

*I love it because the street knows me, and Cheryl that's through the wall<sup>84</sup>, she knows me. I've had a few ones move in and out, but the big guy is alright, [and] there's a couple downstairs, aye spot on. Right now, it's really standard, but last year it was really bad with all the youngsters, and you know where you live, you know your own area. We had a problem with that, but now, it's really strong now. The police are on top of it now so.*

*(Mike, 29)*

Previously these young neighbours caused drug and alcohol-related problems in Mike's immediate community, with regular arguments, physical fights and even deaths occurring in the flats around his. Although, as Mike states, he knows his own area, these events caused him seriously to reconsider the immediate area in which he lives and, despite now being in a better position, he still wishes to move elsewhere. Although he enjoys his home, his experience with some neighbours has tainted how he feels about the space and his trust in those around him. His suspicion of neighbours has deeply impacted on how much he feels that he belongs there, and, despite moving to gain a little more independence, his wishes now are to move back to where he grew up, where he still has friendship and familial connections that he would rekindle should he be able to move.

Admittedly less dramatic, but arguably of equal importance, are Lynne's experiences of living in close proximity to other elderly individuals in her care home. Lynne's aversion to her living arrangements has been documented throughout this thesis, but it is still important to consider how those who, even under the best of intentions, are forced to live with other care home dwellers feel about this proximity to people who are, essentially, their neighbours. The difference for Lynne (68) is that these neighbours are somewhat forced upon her in ways that living in separate homes, within

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<sup>84</sup> A colloquial term meaning literally 'next door'.

individual or family units, are not. Passing pleasantries over the garden fence are instead replaced by communal meal times, socialising events and daily group attendance at mass. Limited decision-making capacity with respect to how often Lynne is forced together with her 'neighbours' leaves her feeling, not part of a home or family unit, but resentful towards these people with whom she *must* spend time at some point in her day. Lynne's is not everyone's experience of such living arrangements. Indeed, Lloyd (71) also resides full-time in a care home, but looks upon those around him as friends, not grudgingly accepted others with whom he must share his space and his life.

It is interesting to note that while 'we', as non-disabled or non-elderly individuals, may feel that living alone results in isolation, it is equally crucial to note that living in shared accommodation does not automatically equate to belonging. Andrews and Phillips (2002:65) critique the provision of elderly residential care as "concerned with custody as much as care", claiming that these care homes hark back to historical institutional spaces of containment, on the periphery of society. Peace *et al* (1997) further add that residential care home facilities systematically depersonalise older people in order to meet adequate care standards. Considering Lynne's lack of connection to her home space, it is interesting to note Twigg's (1997) claims that carers are more likely to be viewed as obtrusive and over-controlling in care home facilities where the boundaries between work place and home-space are further blurred. Conversely, Noro and Aro's (1997) findings in Finnish care homes are more closely aligned with Lloyd's (71) experiences, arguing that most residents are actually happier and better cared for within residential facilities than they had been living at home. The polarised opinions of Lynne and Lloyd seek further to give weight to the claim that one size does not fit all.

Neighbours, then, are important others who can extend a hand of friendship and support which engenders confidence in self-worth and belonging in those with learning disabilities. They can, however, also be the source of fear and agitation which negatively impacts on how those with learning disabilities view themselves as part of the bigger community picture. These insights are particularly crucial when thinking about the neighbourhoods in which those with learning disabilities live, the people they are likely to encounter, and the impact that encounters can have on how they feel about their home-spaces and their role as a member of the community, both positively and negatively.

### *Relationships*

Neighbourly relationships are not the only social interactions which engender feelings of belonging for those with learning disabilities, with most interviewees discussing how they construct and maintain both friendly and romantic relationships through the clubs and groups which they regularly attend. Where these facilities are available and utilised, PWLD are able to broaden their social horizons, becoming part of new networks and creating new connections in which they are active, belonging members; further indicating the importance of the pre-existing 'surface' of provision and raising questions again as to the usefulness of learning disabled-specific spaces for those involved. In general, those interviewed took part in activities which were designed for those with learning disabilities, like Aimee (29) attending Dates 'n' Mates and Amanda (48) at Enable, with only a small number partaking in groups or clubs which included those without learning disabilities, like Darren's music class and Kim's (47) snooker club. Although this may deviate somewhat from the all-encompassing 'community' which was originally envisaged by changes to learning disabled residential patterns, as discussed in Chapter 3, the sense of belonging and community created within these places builds an alternative space for

the creation of meaningful social interactions which matter most to those with learning disability.

For many of those interviewed, these groups or clubs represent spaces of opportunity in which the potential for friendship and learning disabled understanding can safely be sought out. When asked about the walking group which she attends, Mae explains:

*It's exercise and you meet people and maybe build up a friendship with them. You do meet people with dogs and stuff like that, especially down the dam, you meet a lot of people. No it's just to try and build up a friendship with somebody.*

*(Mae, 50)*

Not only does the walking group serve as exercise for Mae, but also presents an opportunity to explore new places and new people in an environment where she is comfortable. By venturing further than she may do alone, Mae becomes more confident of her abilities to move around the area in which she lives, building trust in her surrounding environments and, importantly, the people within them. In knowing 'her town', in which she belongs, Mae is able actively and confidently to seek companionship.

Similarly, Amanda (48) speaks fondly of the numerous groups and clubs which she attends, the experiences that these have afforded her, and the friendships which have begun within and blossomed outwith these spaces. The local day centre, which she has attended for a number of years, provides Amanda with a stable weekly routine, including yoga, arts and crafts, and cooking among other activities. Through these activities she has developed a constant friendship group with whom she regularly attends lunches and events away from the day centre setting. For Amanda, the day centre space has provided a unique starting point from which to build her confidence, connections and relationships, in complete opposition to the suggestion that day centres are always merely holding spaces for

those who do not fit into the ‘normal’ patterns of daily life. Admittedly, the experiences offered within day centres are variable and noticeably different as the demographics of the local population change. Arguably, the services provided within more deprived areas of GG&C offer much less in the way of opportunity, invariably related to the impact of budget cuts and competition for staff (also noted by Hall, 2007 and Power *et al*, 2016). These services are no doubt also constricted into closure by cut-backs to services and public facilities (see the discussion in Chapter 3 on Austerity and Welfare reform). A review of day services by Glasgow City Council surmised that the reduction of day centre services would be the best way forward since, “If [service users] were being assessed for the first time today, then in most cases service users would not be assessed as needing full time day services” (Idascotland.org, 2013). Not only does this report fail accurately to account for the numbers of PWLD who use day centres full-time – 21% of the overall PWLD population (SCLD, 2011) – the use of the word “if” lays bare the fact that Glasgow City Council has consistently failed to conduct ongoing assessments of need relative to service provision. Moreover, LDA Scotland<sup>85</sup> (2015) argue that the council’s Resource Allocation System, seeking to match needs to services, is a failed attempt at personalisation which uses a point based system where it is almost impossible to score 100%, so as to receive the maximum budget to spend on day services. In the Equity Impact Assessment (2013) produced by Glasgow City Council, the latter too admit that the increased cost of services, likely to occur as a result of benefit reforms, will have real implications affecting who can afford access, while simultaneously suggesting that care ‘clients’ can, potentially, expect a lower standard of care. Worryingly, LDA Scotland (2016) argues that this Equality Impact Assessment was not made available to councillors prior to the decision to close services.

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<sup>85</sup> Learning Disability Alliance, Scotland are a learning disabled advocacy group ([www.idascotland.org](http://www.idascotland.org))

The freedoms afforded to Amanda (48) in her decision-making capacity, including availability of well-maintained services and relative ease of access to such opportunities, affords her confidence, rebounding into how she sees herself as a learning disabled person who experiences a life in which she belongs and in which she is fulfilled. For others, this access is hence not so easily attained, reiterating the geographical importance of where one lives to availability of services, a 'where' that ultimately impacts on micro-scale feelings of belonging.

Groups, clubs, classes and day centres can all be recognised as community spaces in which friendships can safely be forged and tested, and often these friendships move beyond the confines of the organised groups, combining home life and social life, so creating networks of trust and belonging. Barbara describes her relationship with a now close friend:

*I mean Anne goes with me for the doctors and she comes with me today to get my blood taken. Basically, she should have been my sister; she has never been away from me, she is with me all the time.*

*(Barbara, 48)*

Barbara and Anne met at an English class designed to improve their literacy skills and to develop their spoken confidence. As well as achieving many personal goals, they also forged a friendship which moved beyond the group and into 'the community', creating extended networks of support in which Barbara, and others with learning disability, can feel that they belong as mobile and participating members in communities of their choosing.

Furthermore, romantic relationships can also flourish through organised group settings, with those interviewed (of whom 3.5% discussed being or having been in relationships) were unable to imagine how they would have met their partner otherwise. Both

Aimee (29) and Grant (29), in particular, spoke of relationships which began as friendships within groups (Dates 'n' Mates) or in the classroom, but then developed 'in the community' and away from the organised group space. For both respondents, these relationships solidified their connections outside of the home space, while also expanding the scope for their future selves, with Grant (29) now imagining a life away from the stable and familiar support structure of home, moving in with his girlfriend, a move he had never before entertained. These 'normal' rights-of-passage into adult life are not experienced, nor looked for, by all respondents. Nevertheless, it is clear, from the manner in which these relationships are discussed, that a sense of normalcy is achieved which speaks to a feeling of belonging; belonging not only within a partnership, but also within the parameters of 'adult' in adult-type relationships. Indeed, the ideas of owning one's home, getting married and having children are not reserved only for those without learning disabilities; and, although it may seem obvious, many of the aspirations of those with learning disabilities are normal in every mundane detail of the everyday, even if how exactly they may achieve such goals seems non-standard.

Perhaps surprisingly, despite their close contact, many of those taking part in the research spoke very little of the relationships between themselves and their carers, rather discussing and commenting upon the care which they received in general. Focussing on the idea of community, it is pertinent to question where exactly these non-familial carers fit into the lives of PWLD; asking, whether or not carers are considered part of the neighbourhoods and communities in which PWLD circulate? Darren, Kim (47) and Wilma (23) speak of their carers in a purely functional manner, discussing their relationship as simply that of service user and carer. On Darren's part, there is a strong distrust of carer motivations, while Kim is confident in her ability to signal her own need for more care. Wilma, having managed without

carers for most of her life, reports that she “hardly ever sees” her carers, really only needing them to discuss her medication. In these circumstances, carers are aligned more with the invasion of the medical sphere into the private spaces of the home, as opposed to carers representing help from the community, as discussed previously with regards to neighbours. In a small number of cases, however, the relationship between PWLD and their carers moves beyond the somewhat distanced professional frame, towards a genuinely caring and friendly relationship in which the former feel a sense of comfort and familiarity with the latter. Maria (64), in particular, highlights the importance of one particular care worker to her when dealing with grief, stating simply: “She was so, so good, I don’t think I could have done without her, I couldn’t have got through without her”. In her opinion, the carer had surpassed the call of duty to ensure that Maria had an ally in the process of grieving; a resource of strength into which she could tap when it was needed most. By being alongside her throughout the grieving process, even carrying out simple tasks such as selecting the correct shoes for the funeral, Maria felt emotionally supported by her carer at a time when alienation could have become a critical issue. In the act of showing Maria that she was not alone in her time of need, she was encouraged to imagine a life of her own, on the other side of grief, a life in which she would once again belong as she had done within her family unit. In Maria’s experience, her carer represents an extension of community within the home-space, bringing the outside in, so to speak, and allowing her to feel secure and supported, even in times of grief.

Similarly, Scott (20) and Nicolle have a very close caring/cared for relationship in which they hold shared memories and can tease each other about past events. Nicolle shows a genuine care and patience with Scott, allowing him to express and check his feelings, using her almost as a social barometer for how he should feel in certain social

situations. Nicolle explains things to him in a non-patronising fashion which allows him space to ask about those things of concern without him feeling that he is either stupid or strange. Promoting this normalcy allows Scott never to feel that he does not belong in certain circumstances or when he experiences certain 'out of the ordinary' feeling or emotions. This is not necessarily a discussion of belonging *per se*, but rather the small acts of kindness in her manner which never make Scott feel that he is 'abnormal'. Scott and Nicolle's relationship challenges the "simplistic/asymmetric power relations" of carer/service user, not necessarily wholly redressing the balance, but recognising that agency is able to "ebb and flow across time, and across different spaces" (Askins, 2015:472); as Bondi (2008) suggests, making visible the connections between care and power. Drawing further from the work of Askins (2014, 2015, 2016) on the quiet politics of befriending, the relationship between carer and service user is established in the mundane spaces of the everyday, allowing time in which people "discover each other as multifaceted, complex and interdependent" (Askins, 2015:476). A carer's role as paid support cannot go unnoticed, but, as can be seen from how Darren, Kim (47) and Wilma (23) related to paid carers, there is not always the same rapport as has arisen between Scott and Nicolle, nor the same discovery of common ground which encourages, supports and grows a sense of small-scale belonging, then reflected in learning disabled interactions at the community level.

### *Community relationships*

Through feeling a sense of belonging, these small-scale, familiar relationships can create a base from which those with learning disabilities are able to build a spectrum of meaningful community relationships in which they are actively involved in the running of community projects or feel part of community life. For John, feeling part of the community is as simple as those around him saying 'good

morning' and 'hello' as he passes by on his way to various clubs or daily tasks. These small-scale pleasantries make him feel more comfortable with his material surroundings, giving him a sense of visibility and thereby making him feel less alone and less 'different'. For Barbara (48), there was the realisation reached in the interview process that she, a person with a learning disability, could re-establish the community bingo games which had previously brought together lonely and vulnerable people from her community, and which were now sorely missed. Although I cannot say for certain whether Barbara ever brought these plans to fruition, I can say with certainty that she felt empowered to make these changes at the community level for her neighbours. A key consideration here is that there are many ways in which PWLD contribute *to* their local communities, to specific activities within them, sometimes with a caring dimension; as such, the story is not about what support and care they receive *from* the community.

Community relationships are also built and maintained for many respondents through church attendance and church-run community groups, which take place not only in church settings, but also permeate into the surrounding area. Kim (47) has worked, and continues to work, hard to raise funds for and with her church group in order to allow them to keep afloat many of the clubs and groups in which she is involved. When asked, Kim cites the church as the main source of her pride and sense of community. Likewise, Maria also speaks fondly of her involvement in her local church:

*F: I do the collection and we organise bus runs. We had one in August there and we had one earlier in the year and I help out, and [the minister] said 'can I help out with the collection?'. He said 'we have another job for you, can you do the offertory?' Oh that's alright, that's two jobs I get done.*

*V: Do you like having that responsibility?*

*F: Yes, they all get on great with me, you know, they all get on great with me and we do all sorts.*  
(Maria, 64)

Maria enjoys not only having responsibilities but also being trusted to carry out meaningful tasks for those around her in her congregation whom she considers her friends. Through this involvement in a (dimension of) community close to her heart as a person of faith, Maria feels that she belongs in social spaces of importance to her.

Throughout the thesis, Darren's preference for living in smaller, village environments has been charted, with the sense of community which these smaller spaces offer allowing Darren always to feel that he belongs as part of the overall, small-scale mobilities of village life:

*We go to the shops, we go to the pubs, we go to the clubs, we go to whatever's on. The bowling green as well, we go to all these things, play music ... well we play for fun, I play for fun, music, we have dances at the village hall, we have all kinds of things going on; it's a right community where things go on.*

(Darren)

By taking part in the ebbs and flows of village life, Darren feels socially closer to those around him, imagining his place within the village as a small molecule in the creation of the overall atmosphere of togetherness which the village evokes. He argues that it is impossible to be alone in the village, certainly not in the way that he had felt in the city, since lack of inclusion within the rural community would be noticed and concerns raised. Belonging in this way is exactly what Darren needed in order to feel fulfilled and important as a learning disabled person who had previously been bullied, seemingly living out the stereotypical (but not necessarily entirely untrue) distinction between *Gemeinschaft* and *Gesellschaft* which have been routinely 'mapped' onto the rural and urban respectively (see Parr and Philo, 2003; Parr *et al*, 2004).

Belonging is further experienced by respondents with the help of Local Area Coordination (LAC) wherein those with learning disabilities have an appointed person, familiar with their immediate locality, who helps them to acquire roles within the community which they feel would benefit their lives. Hall and McGarrol (2012), drawing on Roulstone and Prideaux (2012), argue that PWLD, in a continually neoliberalising environment, are considered as part of one of two spheres; either legitimately *able* to work, or *unable* to work. Entangled within these spheres is the orthodox notion of care as a form of security for those who cannot properly contribute to society (Conradson, 2003). What Hall and McGarrol (2012) propose is an expanding third sphere which captures the experiences of those PWLD who are neither in paid employment nor awarded social care. It is in this third sphere that LAC can best be utilised, carrying forward an ethos of progressive localism (Featherstone *et al*, 2012) to provide “support, guidance and ‘brokerage’” (Hall and McGarrol, 2012:1277) which challenges the deterministic relationship between paid work and social inclusion (Levitas, 1998), and further encourages multi-scalar belonging. With the help of a LAC, Aimee (29) was able to find many avenues into the community which she was unaware were available to her, including obtaining a part-time job at a local school and attending Dates ‘n’ Mates, through which she met her partner. Having another person who was able to open up Aimee’s social worlds allowed her to feel like a ‘normal’ adult in these ways, feeling that she belonged as an ‘ordinary’ person.

Moreover, these interactions outwith the home-space, and within community spaces, build a sense of social responsibility, meaning that those with learning disability do not simply passively accept friendship and solace from belonging within communities, but indeed also have something to offer back; something about which they can feel pride. Kim describes her role in a charity church group,

*P: People go round the houses and you get someone in a wee bed and...I'll show you, we help certain people.*

*V: To look after sick members of the church?*

*P: Yes.*

*V: And you help out with that?*

*P: Yes I do.*

*V: And what do you enjoy about doing that?*

*P: To help out people who can't get out a lot that's why.*

*(Kim)*

Kim therefore experiences a reciprocal relationship within her church community, a group from which she has received help in the past but to which she can now give her time in a voluntary capacity. When asked if there was anything which would further her feelings of belonging in the community, Kim suggested that she would like to help others with learning disabilities as she has been helped in the past, teaching them to shop independently, accompanying them to the bank and helping to sort any problems that they may come up against. This answer illustrates the power of community involvement and sense of personal growth which Kim feels she has achieved as part of the various groups which she attends and, furthermore, hints at the kind of reciprocities that can be built in the learning disabled community.

Personal development through community belonging was discussed by many of those PWLD taking part in the research. Scott (20) explains that he is now part of the newsletter team at his Sense<sup>86</sup> club where he interviews other members of the group, undertaking various tasks and writing about them. Many of the roles undertaken in this capacity as a contributor push Scott's personal and social boundaries, both in his language and communication skills and in conversing confidently with others. Scott (20) can see the benefits brought to him, and he

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<sup>86</sup> Sense Scotland work with children, young people and adults with communicational problems in order to ensure that they learn ways in which to use their voice (<http://www.sensescotland.org.uk/>).

feels pride in circulating his work to friends and family of the group, forging connections and rapport with his own learning disabled community. For others, their levels of personal development occur on a smaller, more personal, scale, but are still essential to their experience of belonging within the networks and communities through which they move. For Colin (55), the opportunity to create and to maintain the gardens around his group home offers an ongoing sense of achievement, as well as bringing happiness to others living with him who regularly use the gardens. Having impact in this way does not just make him feel that he belongs, but, importantly, that this residential space belongs to him even though he shares it with others with learning disabilities.

Similarly, Robert's small-scale experience of respite care exemplifies how community involvement, or rather, involvement in community practices, can develop skills on a personal level:

**Father:** [...] Since he's been going to the Respite<sup>87</sup>, he used to sit in his room [in the Respite centre] in the beginning with his own DVD, [but] now he's mixing, which again, getting him ready for moving on when he goes in to care<sup>88</sup>, it's a good thing. As we were saying, when he first went in he would only sit in his room and we'd put DVDs on.

**Mother:** Well it was the front door at first wasn't it?

**Father:** Yeh, but after that he was still sat in his room, but now he's coming out and sitting with the rest of them, he's really mixing, he is a sociable person though isn't he? He really loves people, he loves people watching.

**V:** Do you see a difference in him since he went to respite?

**Father:** Oh yeh, he seems to have grown up, he seems to be more mature.

(Robert's Parents)

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<sup>87</sup> Robert (34) attends residential respite services for adults with learning disabilities for two nights once a month.

<sup>88</sup> As his sole carers Robert's parents are preparing him and themselves for a time after their death when he will still need 24-hour care.

Despite clearly being a place which first intimidated Robert, as evidenced by his insistence on staying beside the front door on his first night, involvement as part of a group of learning disabled people experiencing similar things to himself has allowed him to build social skills not previously utilised; skills which will serve him well as his social circles inevitably change. These examples of personal development occur across different scales with different levels of impact within the communities where PWLD are living and moving, but it is, without doubt, a sense of ease and confidence, related to belonging, which has facilitated and maintained these community relationships, so allowing PWLD to live the life important to them, evidenced further in box 6 below. Mike (29) perhaps sums this up best saying: “I’m meeting a lot of different people, people that have got too much to lose<sup>89</sup> and I don’t want to hurt them”, suggesting that meeting an array of people within his community has changed his outlook, making him realise that he too stands to lose out should he go back to the reclusive way in which he used to live his life.

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<sup>89</sup> This sentence does not mean that the people themselves somehow have “too much to lose”, but rather that he now values them so much that he does not want to lose touch with them.

### Box 6: Case study with Lawrence

Community involvement for Lawrence is essential to his experiences of belonging, and in particular he highlights a number of non-learning disabled groups, spaces and places where he feels actively involved in the everyday comings and goings, all meriting attention here. Specifically, he highlights the Dundee Rep Theatre, the space in which his learning disabled drama group meet, and his church. Although his drama class meet at the Rep, the relevant interaction of which Lawrence speaks here take place out of this context and with those others without learning disabilities who also use the spaces of the theatre.



Here, Lawrence is pictured with two people who work in the Rep café, and he explains that “one of these people are the lady who works here, I know her from around and speak to her when I see her”. These small-scale interactions with others are pivotal in his sense of belonging. Like Darren (42), Lawrence draws pleasure from knowing that he is seen and recognised within the community, even if only in passing pleasantries. This point is further evidenced by the choice of seat adopted in the above image; he tells me, “I like to sit at the window and see people – they give you a wave”. Moreover, showcasing the gentler side of his personality, Lawrence explains that he “like[s] to make people welcome by saying good morning. It makes me feel good to welcome people”. Ensuring that people are not ignored performs a key role in ensuring that he too is not ignored, all forms of active community-building encouraged by his sense of comfort and belonging in the Rep theatre.

Lawrence’s sense of community belonging is further deepened by his attendance at church: a Sunday for morning mass and prayer, and a Tuesday for his prayer group. Again, the church represents a non-learning disabled space in which Lawrence derives a source of comfort, support and belonging, seeking out his own small-scale community of like-minded religious people. It is with his church group that Lawrence enjoyed a trip to Lourdes, an experience which he describes as a “once-in-a-lifetime” trip to a place of extreme religious importance with people

who appreciated its significance. A trip abroad such as this is not something which Lawrence had been able to experience before, or has experienced since. His move to Charleston (see Box 2) somewhat interrupted his community connections with his old church, and he explains that tried to attend the church in his new local area but it was “just not the same”. It is clear, then, that his connection to the community of the church is not simply attributed to shared religious beliefs, or that any church would do; indeed, it is the connections between particular others within this religious space, built up over time and maintained through shared memories and experiences, which marks this as a place to and in which Lawrence belongs.

### **Barriers to belonging**

As ever, feeling that one ‘has a place’ is no straightforward process of community inclusion which automatically instils a sense of belonging in those with learning disability, for many barriers exist which impact on how such individuals experience their varying community-scapes. This chapter has previously discussed the role played by groups and clubs in the creation of safe spaces which can influence feelings of belonging through safety and comfort. It is clear, however, that group spaces are becoming less influential as they become less available and the landscape of provision more uneven, negatively impacting on opportunities for finding and creating community-building environments. Undeniably this contributes to the psycho-emotional impacts of barriers to ‘being’ and ‘doing’ discussed by Thomas (1999) and Reeve (2012). Additionally, Hall (2004) suggests that the importance of alternative learning disability spaces, such as groups and clubs, are underplayed since they seek to support the agency and strengths of PWLD which work to create a strong sense of learning disabled-focussed belonging (Colley and Hodkinson, 2001). Indeed, in the now politically more mainstream promotion of learning disabled integration into mainstream spaces, Hall (2004:300) argues that this simplistic view fails to recognise the “structural constraints, institutional discrimination and individual stigmatisation” faced by PWLD. Without their own dedicated spaces, many PWLD are unaware of how best to change their lives to include those things which would

make them more fulfilled. There is now an impulse towards integrating PWLD into non-learning disabled spaces (communities) predicated on new, but arguably problematic assumptions about normality and inclusion (Hall, 2004). This is not to argue that PWLD should never attempt social inclusion in non-learning disabled spaces, but rather it would seem that policy frameworks *still* need to be less prescriptive about where PWLD *should* be, creating instead enabling environments (Swain *et al*, 1993) of all types which promote and encourage learning disabled participation at diverse scales; in doing so, reducing multiple barriers to belonging.

In Eilidh's (29) experience, for instance, it is simply lack of opportunity which continues to restrict and tighten her potential learning disabled and non-learning disabled community spaces of belonging. In the localities through which she is comfortable and able to travel, there are a limited number of age appropriate groups which spark her interest. This therefore limits her desire to move out from the home-space and to mingle with others her own age or with similar hobbies, restricting the ways in which Eilidh experiences her local environments and the potential connection which she may build there.

Relatedly, Jamie (52) blames council cutbacks for the closure of various groups and clubs which he used to attend, claiming "everything is stopping". These opportunities have either closed or merged across different localities, forcing unknown people and environments onto him in a manner disconcerting to him or, alternatively, leaving him with nothing to do outside of the home-space; a worrying outcome in the Scottish context, given Mencap's (2012) findings that a quarter of adults with learning disability in England spend less than an hour outside their homes. Power and Bartlett (2015:4) describe these spaces as "place-communities", small-scale spaces in which othered groups can find a sense of

belonging, recognising that there are “multiple cross-cutting[s] and at times contested ‘interest communities’ and ‘communities of attachment’” which shape belonging. The reduction of spaces for such interactions further limits opportunities for PWLD to establish and maintain belonging in groups and spaces of importance. Like Hall (2009) and Power (2013), it is crucial to recognise that, although learning disability-only spaces may encourage dependence on such spaces, they also provide important hubs of support. Local council cuts and a decline in formal services (Power *et al*, 2016) continue to disrupt social practices of PWLD which encourage belonging, further reducing the mobilities of those with learning disabilities and their sphere of influence to the home; a potentially regressive step towards the home as a place of isolation not empowerment.

When asked about community feelings in general, Barbara (48) similarly argues that the lack of provision of any activities which could widen her social circles hinders her desire to be an active community member. Although Barbara speaks fondly of friends in the one group that she does attend, she feels that her social worlds are too small and too distinct, her lack of mobility hindering her ability to meet friends and neighbours just in passing, leaving her unable to build relationships in the everyday mobilities of daily life which would make her feel that she belonged in her neighbourhood, as opposed to merely residing there.

These views are similar to the feelings expressed by Mike (29), who worries about his friends who live nearby without access to the sorts of services which have helped him to move forward in his life. His assertion that his friends *need* to move out from this neighbourhood provides support for the claim that opportunities for the creation of self-made networks, fostering connections through groups and activities, are essential to the sense of belonging and happiness experienced by PWLD in their everyday societal connections.

### *Bullying, stigma and the lasting legacy of attack*

Experiences within the local community also potentially have disruptive influences for belonging, when those with learning disabilities feel attacked, self-conscious or belittled by those with whom they come into contact. As opposed to building connections, such experiences can cause a breakdown in communication and a reluctance further to explore those spaces which hold the potential for community involvement and a sense of belonging.

The positive impact of group spaces has been highlighted above, but Darren (42) speaks of experiencing or witnessing stigma and bullying for being a learning disabled person, even within these spaces. Despite attending such groups in order to gain knowledge, meet new people and move his life forward in a positive way, he states that “you learn to just ignore it and work hard”. Even taking part in Growing Concern, a course for gaining gardening qualifications, Darren mentioned that he felt “belittled” by others on the course. He claims that he simply has to move beyond the bullying which he has come to expect, and to continue to take part in activities from which he gains enjoyment and fulfilment. While Darren claims that he is happy to ignore those who spread hate against him, and learning disabled people in general, it is clear to see how this hate could affect the mobility, decision-making and belonging experienced by others who do not share the same resilience, potentially also further limiting the public spaces in which those affected feel that they belong.

Similar experiences have, in the recent past, impacted on how Barbara (48) thinks about and interacts within the environment of her local community. Linking back to earlier discussions of *Gemeinschaft* (Parr and Philo, 2005), becoming visible as a learning disabled person can have both positive and negative impacts. Having been wrongly

accused by the police based on a tip off from another member of the community, she no longer feels confident in her connections within community spaces, instead feeling watched and studied by an unseen other. She states “it’s just made me kind of frightened to go anywhere. You know they are going to be watching you all the time now”. Rather than feeling protected, she feels victimised by the police and by her community, changing the way she views socialising and mingling with those around her in community spaces where she had previously felt safe. The use of the word ‘they’ is a clear indication of the separation Barbara (48) now feels between herself and those around her, and about the community relationships in which she no longer has trust.

Aimee (29) has been influenced in her movements around her community, and so, relatedly, in her sense of belonging, following a sexual attack outside her home, as discussed in Chapter 6. Since this event, she has become more isolated and restricted in her social circles as her concern about the motives of others has risen, making it more difficult for her to build new networks and connections beyond the ones already established. This situation leaves Aimee in stasis, revolving constantly around the same people and places without the confidence to expand her social horizons for fear of attack, verbally or physically. Aimee admits that, since the attack, she has become more lonely as her fears of the uncontrollable outside world have grown, so impacting not only on how she feels about the area in which she lives, but also her own imagined geographies of belonging and self within these community-spaces. Sadly, Aimee is not alone in these experiences. Kim (47) has also suffered attacks on her person and at home which have caused her to lose trust in her surroundings and the people within them. Stones thrown at her windows by local youths unsettled Kim to the point of moving home, a move which Kim felt confident to make but not one which is available to all PWLD who experience such acts of harassment. Instances of violent crime against

people with learning disabilities, like the eventual suicide of Fiona Pilkington and her learning disabled daughter due to neighbourhood bullies (Walker, 2009), and 'mate crime', like the brutal beating, drugging and resulting murder of Lee Irving (Press Association, 2016), continue to circulate in the media impacting on the confidence of PWLD, and their families, further restricting social circles and closing down opportunities for belonging (Thomas, 2011).

*Being lonely and underestimated*

It is not only the fear of attack which has debilitating impacts on belonging, but also the way in which those with whom PWLD come into contact treat their requests and aspirations. In short, many PWLD still do not receive respect for their needs or their rights as contributing societal members who are, in the main, chronically 'normal' in their everyday mobilities, even if their practices can seem 'non-standard'. Most who took part in the research spoke neither of loneliness nor isolation directly, but rather of frustration and belittlement at the hands of various non-learning disabled actors in their lives. The latter, in their view, continue to undermine or underestimate their abilities, focussing instead on those tasks which they cannot do well, quickly enough, or at all, as echoed by Hansen and Philo's (2007) claims about "doing things differently".

Grant (29) and his Mother explain that he stopped going to a local computing class because they failed to challenge him in any way:

**G:** *We were never doing anything there*

**Mother:** *I think they got left in the corner in front of a computer all the time and they never really interacted with him at all because his speech is that way, you have to sort of sit and, you know, listen to what he's saying, so they never got him involved with anything other than just sitting in front of a computer. I think they were quite surprised when we went to the meeting and [Grant] told them what he*

*thought because they had never actually asked.*  
(Grant, 29)

Being underestimated by those groups where he was supposed to feel most supported left Grant feeling frustrated and undervalued as someone with the ability readily to contribute to the working of the group, should they have taken the time to understand his non-standard speech patterns. While admittedly initially difficult to understand, Grant is prepared to repeat himself slowly and more clearly when asked, so being perfectly able to contribute to any discussions regarding ways in which his life could be improved. By denying him this time, the group had also denied him his place within a community which may well have enriched his life, causing him to seek friendship and understanding elsewhere. Although this class within the local community centre gave Grant somewhere to go with peers, the support there was not aimed at those with learning disabilities and so did not give him the desired outcome. This further highlights the importance of learning disabled-only centres and groups which cater to the needs of this cohort. The veil of inclusion, simply in being 'allowed' to use non-learning disabled spaces, is not always enough when extra support is genuinely required, a theme which will be revisited later in the thesis.

For others interviewed, feelings of belonging changed when interacting outwith their normal community spaces, causing tensions and upset. Mae speaks about her experiences of dealing with a new receptionist at the local paper with regards to a story about her charity abseil:

*[...] that woman cut me two or three times, it was the way that she spoke to me, as if she was looking down on me, as if I was worth nothing. So she didn't make me feel part of the community; she made me feel as if I am doing [charity work] and I am being smart, but I am not being smart, I'm doing it because I am proud, you know what I mean. I said that to her, 'I*

*am not being smart, I'm being proud'. She went 'if that is the way you feel, that is your prerogative, but me personally I think you are just doing it to get yourself in the paper'. I said 'you're right enough, I am doing it to get myself in the paper, but not the way you are thinking'.*

*She was basically kind of raising her voice, but looking right in my face sort of thing.*

*(Mae, 50)*

Mae very much feels part of her Deafblind Scotland<sup>90</sup> community since they are “more or less in the same boat as each other”, but, could not help feeling belittled and ostracised by the newspaper; an organisation which she views as the heart of the community in which she lives. In sharing her accomplishments with those around her, Mae continues to try to educate people about the work done by Deafblind Scotland to help those suffering from hearing and sight impairments within the community. The above interaction caused Mae to feel insignificant and almost ashamed of her achievements in raising money and about the profile of a charity which has helped her in various ways to lead a more fulfilling life. While deeply subjective, such experiences happen with varying severity for most of those PWLD who took part in the research, and so are essential in understanding more about the fragility of belonging for those with learning disabilities.

Lloyd's (71) experience of barriers to belonging is somewhat different to the others. Although he feels well settled as a member of his nursing home community, his connection to his old communities outside of the home have slowly diminished over time, leaving him unable to imagine how it was before he moved out of his own home. He no longer goes to football matches, which had been very important to him when he lived alone, nor does he see any of his family who

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<sup>90</sup> Deafblind Scotland is a charity and advocacy group who support and campaign on behalf of people with dual sensory impairment ([deafblindscotland.org.uk](http://deafblindscotland.org.uk)).

choose not to visit. The spaces in which he used to belong are no longer available to him as his mobilities have reduced, so changing his perception of his previous life to that which happened 'out there', while his current reality is played out in the 'in here' of the nursing home (Andrews and Phillips, 2002). It is therefore important to understand the ways which belonging can change with residential setting, although, as in Lloyd's case, these changes are not necessarily unwelcome, but regarded simply as a 'natural' progression.

### ***Home***

As Heidegger (1993) posits, building and dwelling are not one in the same, in that a house is not automatically a home and, as such, it should not be assumed that PWLD (and those without) obviously feel a deep sense of belonging in that space. For many PWLD, this is not the case and we can begin to see here, more than anywhere else, the clear distinction between house (a building for human habitation) and home (a lifetime dwelling shared by friends or loved ones). These terms can appear almost similar, but – echoing claims made right at the outset of the thesis – it is in the messy spaces of the in-between house and home that the intricacies of belonging in and at home begin to become apparent. Easthope (2004: 135) argues that home is both socio-spatial and psycho-spatial, and so to understand a person's connection to home is to begin to recognise their "social relations, their psychology and their emotions" through which lived experiences can be understood. Moreover, Easthope (2004) warns against static definitions of home, drawing on Lawrence (1985:129) to suggest that the study of home is one of "continuous processes rather than isolated actions". One can move house without it being a space which represents 'home': a house may never feel like a home, in so far as the latter is meant to index a site of active, comfortable, secure dwelling. This of course is to presume that 'dwelling' is always about feelings of meaningful belonging – another perspective could be about dwelling

as itself contested – dwelling can be done unhappily, riskily and dangerously. It is therefore essential to present work on home as it is understood in different contexts by different people and, in understanding these spaces for PWLD, we, as geographers (and beyond), can begin to delve into those idiosyncrasies which make people feel that they belong (or indeed do not belong).

This is not to suggest that having one's own home automatically instils a sense of belonging, nor that moving home can necessarily improve one's sense of belonging; indeed, it can be dislocating of such a sense. Darren (42) discusses how moving home was a process of learning new mobilities and routines as a person living alone, which he argues "you just have to get used to as you get used to everything else". When Darren moved from his mother's house in his early 30s, he moved with the family dog, taking a little piece of his old home into his new house – a familiar companion in unfamiliar surroundings. His dog kept him company, allowing him to find a small sense of normality as he adjusted to his new situation. Over time, Darren's growing familiarity with the people and places which surrounded him allowed him to build rapport with his house which made it feel like *his* space, indeed a place in which he belongs, a home.

Fostering such connections of belonging in existing home spaces is further discussed by Stuart (42) as he talks about the community sense of responsibility involved in living on a shared landing within a block of flats. He explains:

*Each of the neighbours all make sure our doors are all right. We don't get involved in any trouble; basically that's it, we all look out for each other. If there is any complaints, we go through the caretaker at the [housing association] about our properties; if there is something wrong, or if there is something not right, we go through the housing association officer.*

*(Stuart, 42)*

Despite the house not technically being owned by Stuart, he experiences a sense of pride and comradeship which encourages him to feel that the space very much belongs to him. The technicalities of ownership are not in direct correlation to a sense of belonging experienced and so are entirely secondary here, but it is worthwhile noting that the more precarious terms of occupation experienced by many PWLD may impact on feelings of security in that space as they are vulnerable to being moved on by the decisions of others. Even so, tenancy is very rarely even brought up as a barrier to belonging by respondents. Instead, it is the space itself and the people around and within it which offer these experiences; home becoming a place to which you belong and which belongs to you.

Throughout the thesis home was also discussed as a space which glued a legitimate belonging to the label 'adult', a material stamp which indicated to others that 'you' should be taken seriously. Carol (29), among others, spoke of the influence of others in making the decision to move out of the family home and into her own home, and her mother explains that "she is looking forward to it, she loves it, she loves the idea because she knows [her siblings] are out the house". Having watched her brother and sister move out and start their own families, Carol is keen for the same to happen to her as she 'moves on' with her life. Similar stories were also told by Wilma (23) and Maria (64) who, having watched friends of a similar age and level of disability move into their own homes, felt that it was time for them too to take on this role of adulthood. Stemming from the notion of becoming an adult, the idea of belonging in one's own home is often discussed as synonymous with a new state of independence in which those with learning disabilities can feel more in control of the spaces in which they live. Jean's sense of belonging in her home is grown from the fact that she is able to take walks around her neighbourhood whenever she sees fit, taking control of the spaces around her which she was

unable to do when living in her family home. The neighbourhood in which she had previously lived was deemed by her family to be less safe and the terrain was not suitable for her walking needs. Prompted by her carers and now living outside the protective bubble of the family, Jean is more confident in her ability to access those community spaces outside of her home, obviously increasing her sense of belonging to her home and neighbourhood.

Moreover, home is often discussed as a space which begins to reflect an individual's personality and so makes them happy. When asked about her favourite place in the house, Kim (47) explains that it is her living room, as this is the space where she has surrounded herself with the things that she enjoys. Around the walls are rugs and artworks which she has created herself, collections of DVDs gathered by her and photographs of her and various friends on different holidays abroad, echoing observations by Rose (2003). Having the space to display such personal mementos is what makes Kim feel happy to be home, in a space which she feels belongs to her and 'houses' her memories of a happy life. Germane to this thesis is the fact that Kim has moved house on a number of occasions, but always feels at home in these spaces when surrounded by her personal possessions – her moving landscape may be fractured and even quite chaotic, but her sense of belonging has been more consistent, even an anchor beneath this chaos of movement, not least because of moving with treasured possessions and memories (explored further in Box 7).

Furthering this consideration is the notion of home as a place in which PWLD can feel safe and secure. Both Mike (46) and Claire (51) use the analogy of shutting the door behind them as a descriptor of what makes them happy to be home. Being seen as a place of safety and security is a strong indication that home is a space with clear boundaries surrounding who belongs inside that space and also, therefore, who does not. Safety within the community and the home

were some of the most influential factors influencing how research respondents viewed themselves as fitting into various communities simultaneously, with many of those who took part moving house due to a sense of fear within their home spaces, but wishing to maintain connections with friends and networks already developed. It is therefore important to residential mobility and belonging that it is understood how those with learning disabilities think about their safety in relation to their relationships and home spaces. Although split into three chapters within the thesis, it is clear that mobility and decision-making combine to create environments in which those with learning disabilities feel that they belong.

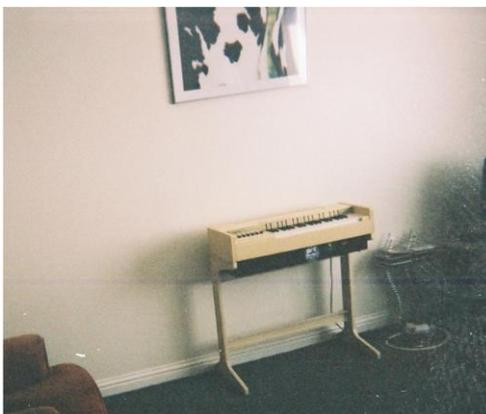
**Box 7: Case study with Lawrence**

Small-scale belonging at home can be essential for PWLD especially, as is Lawrence’s case, when a sense of belonging is not encouraged by the immediate neighbourhood surroundings. Making a house into a home involves a number of intimate interactions and personal encounters which allow the house to reflect something of the person who lives within its walls.



In his photo diary about his home, Lawrence (70) produced the image overleaf of his living room, the angle the picture is taken from, he explains, allowing me to see everything about this space which he enjoys. He tells me, “I like my independence” and “I like to be able to sit at my window and see out, I can watch the kids playing”. This window out into the world serves to connect Lawrence at least in some ways to the spaces outside of his home; a community into which he is still unsure that he fits, but nonetheless of which he wants to feel a part. Furnishing the home with trinkets and memories has

been crucial for Lawrence in making Charleston feel like his home, given the manner in which he left Blackwood Court and the bonds which still tie him to that home, a home which no longer exists in reality. Looking at the picture above he tells me with pride, “I made the dog at a centre I went to for a few years” and “I won that vase in a raffle”, highlighting the important sense of self-confidence and belonging which these seemingly innocuous objects can instil.



Lawrence’s living room is also ‘home’ to his keyboard, an object of further importance which stamps a little of his personality into his home. Having learned to play three years ago from a staff member at the MacKinnon Respite Centre, Lawrence describes the act of playing his keyboard as “joyous”, taking great pleasure in collecting new song sheets for his book and learning to play new songs which he “sometimes play[s] to Tommy [his brother]”. Religion is also an integral part of Lawrence’s life which is further showcased in his home.



Lawrence tells me “I still say my prayers every night” and, as such, this altar in the hallway of his home represents an important facet of his life; the Statue of Our Lady, a souvenir brought home from Lourdes as a memory of his visit there. Not only does this altar make him feel “closer to god” in his home but, importantly, also makes him feel safe, saying “I know I am safe enough [when I see this statue]”, an important item which makes house, home, a place in which Lawrence belongs. The dog, the keyboard and the statue represent small-scale mundane ways in which PWLD like Lawrence (and others) create bonds and connections with their home spaces, growing feelings of safety and security, pride, and belonging. Even when, like Lawrence, there is little in the way of connection to the direct community spaces outside of the home, there are key ways in which

homes support and reflect learning disabled personality and confidence, championing the significance of suitable learning disabled homes. Of course decorating our homes with ornaments and possessions is something that 'we' all do in a way and this is precisely the point; PWLD are not necessarily different because of differing cognitive or emotional processes. There may still be space to argue however, that these small objects of home-making may matter even more to someone like Lawrence, whose other opportunities for self-identification and self-affirmation are relatively constrained.

### *The family home and the group home*

For those living with parents or in a group home, the bedroom often becomes a space of importance in feeling like they belong, since in this space they can arguably 'be themselves'. The bedroom becomes a quiet space where they can partake in the hobbies and pastimes which are important to them, and a space which can be decorated to allow a reflection of their personality; of course, this reflects too their child-like status in some homes. Wilma (23) describes herself as a "bit of a loner", explaining that her favourite place in the house is her bedroom since this is where she can enjoy her own company, spending time on her computer writing Sonic the Hedgehog<sup>91</sup> fan fiction. Here she is free from the worries of being 'abnormal', of having to try to appear that she is feeling well or that she is not worried. The space of her bedroom belongs to her and her alone, at least in her perception, a space given over to her by grandparents and over which she has full control; and so it is a space in which she can be comfortable and is able to show her true self.

Similarly, both Colin (55) and Alexander speak about their room as their favourite place within their residential group homes. Again, both explain that this is the sole space in an otherwise shared home which belongs only to them, a place where they have a say in the décor and can impact on their daily goings-on, allowing it better to reflect their

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<sup>91</sup> A video game franchise made by Sega.

needs and wants. In these rooms, they have access to their own TVs, couches and record players, and so are able to flex their autonomy rather than conform to group consensus. Succinctly put, their bedrooms are spaces in which they feel they are in control, so being able to keep it clean and tidy to their standards, something they are unable to do elsewhere in their shared home spaces. For some PWLD in group homes, it seems that bedrooms can represent small-scale homes, which act as the location for their own autonomous decision-making, a place where boundaries can be set out and maintained (Sibley, 1995), even in shared residential spaces. Of course these spaces in such collective residential spaces can just as easily be isolating as in Lynne's case, as discussed several times throughout the thesis.

### ***Barriers to belonging at home***

Those PWLD interviewed throughout the study express a number of barriers, some large and some trivial, which dictated how they experienced a sense of belonging in the home-space. While many of these barriers are individually experienced, they are very much influenced by happenings and dynamics in wider local, political and economic communities, which act back in on them as they move through their daily lives. Many of these barriers are therefore a source of continued frustration as those with learning disabilities continue to have to fight at each turn to lead a life which is, to them at least, perfectly normal.

One such outside pressure presented itself in the form of Independent Living, the prevalent agenda for those with learning disabilities, many feeling that this imperative fails to recognise that home is the place in which a PWLD enjoys living, not necessarily a place where other outside actors feel you *should* live in order to experience a fulfilling life. Jamie (52) explains that at times he has felt almost forced upon

by the very idea of Independent Living, saying that it is something which is continually discussed by both service users and carers at his local centre. This is not something that Jamie has the desire or need to consider, feeling that his best sense of comfort and safety occurs when living at home with his brother. While he states that he would not describe himself as living independently, he does not feel that a lack of independence in any way hinders his life. Rather, this matter burdens him with more worry, as he imagines readjusting to a life alone in which he must rely solely on strangers to supply his care. Jamie's story is one which makes it increasingly essential that policy does not demand Independent Living, at least not in the same way that policy shifts effectively demanded the closure of long stay hospital facilities, as discussed in Chapter 4. Instead, it should leave room and make provision for those who may wish to live independently, or indeed, dependently, in various forms, accepting that different states of 'normal' exist for different PWLDs, making them feel like they belong in whichever living arrangement so suits; thoughts echoed by Hall and Wilton (2016).

#### *Home as a changing landscape*

Many respondents who did not have a choice in the movement of their residential setting speak of their initial unease in a space which they felt was not their own, and in which they could not be themselves, and so belonging is evidently a changeable state which ebbs and flows dependent on the where, the when and the decision-making input of the individual. Lloyd (71) and Claire (51), among others, speak of their new places of residence as feeling strange and unhomely<sup>92</sup> as they learned to get used to their surroundings. Places which were new and unknown were therefore spaces in which they did not feel that they belonged or that these spaces belonged to them.

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<sup>92</sup> The category of homely, or *unheimlich*, is central to psychoanalytic theory.

Maria (64) experienced similar feelings with regards to her home-space, as the death of her parents meant a re-imagining of what home was, saying “not having anybody in when I came home. That was strange”. While the home space itself had not changed, Maria’s feelings towards it altered, since part of her sense of belonging had clearly been anchored in the safety and familiarity provided by living alongside her parents. As MacHale and Carey (2002:114) point out, losing a parent for a PWLD can also mean the loss of a “confidante, their home and possessions, and a familiar neighbourhood and routine”. While very well supported through a time of grief, Maria admits that it took her a while to feel that her home was hers again, to stop waiting for her parents to return and to take charge, as they had done previously. Like those without a learning disability, bereavement can impact on PWLD in multiple ways, further complicated by their unknowable capacity properly to understand the impacts of loss (Koeppel and Hollins, 1989). For PWLD, death can represent not only the loss of a parent and carer, but also the loss of critical parts of their identity. As has been noted throughout this chapter, identity, home and belonging are inextricably bound to one another (Easthope, 2004) and damage of one of these framing ideologies may have innumerable impacts on the other as PWLD are forced to encounter new people, new routines and, potentially, new places.

When changes in residential landscape are unwanted, some PWLD interviewed felt a loss of control which hindered their feelings of belonging within their new home-space. Lynne (68) feels that she is unable to control who moves in and out of her personal space, despite having the room decorated with trinkets and memories which make it personal to her. Her sense of belonging within her nursing home is further hindered by not being called the name that she prefers, the name which previously had been representative of the comfort and

safety of a place she views as her real home. Belonging at home is not just about control, then, but about familiarity in a space where, for Lynne in particular, one can be their truest version of themselves. Home must therefore also reflect back senses of themselves, so allowing a sense of belonging to develop.

Respondents also suggested that it is harder to feel that you belong when there are small things that you rely on others to do for you within the privacy of the home-space. Here the issue is not so much care but rather odd-jobs which, when left un-done, can destabilise the bonds of belonging which usually exist. John speaks of needing a new cupboard in his flat and the requirement to go through his housing association in order to have it fixed. The time-scales involved in this respect leave him frustrated with his living arrangements, since they are not just the way he would like them. Similarly, Mike (29) felt the same disconnect when waiting for his housing association to fix a leak which caused water damage in his bathroom. Although relatively easily solved, these issues are ones which stood out to those interviewed, changing how they viewed their home-space and felt about their happiness within that space. Again, these stories are not so different the experiences of any home-owner or tenant, but what must be noted here is the likelihood for PWLD to be living within rented accommodation which is unsuited to their needs, and where they are have limited power to enact change or continually push for more appropriate service.

Changes in housing can also cause barriers to belonging when the homes themselves are not suitable in allowing the PWLD to live a life where they feel happy and supported. Barbara (48) continues to feel increasingly trapped within her home space and therefore unable to attend clubs and groups, or to mingle with the local community in a manner that she would wish. The hills which surround her home make it almost impossible for her to explore her localities by foot, and

therefore she feels that she is also missing out on the interactions with others which might occur in these spaces of the in-between. In this instance both the house and neighbourhood suit Barbara's needs and aspirations, but the simple geography of the land hinders her ability to take part in experiences which would make her feel that she belongs at home.

It is not therefore simply a given that the provision of a house automatically equates to feeling that 'you' belong at home. Rather, belonging involves an intricate array of emotions and experiences falling into alignment. While this highlights the complexity of choosing, or indeed building, suitable and appropriate homes for those with learning disabilities, it is not a task so hard as to preclude asking PWLD themselves for input and advice, which might then result in more positive experiences and outcomes for quality of life.

### ***Belonging, community and home***

Throughout this chapter there has been an important interplay of words which relate to the notion of belonging, even if not always saying the word itself. Instead, respondents used words such as friendship, community, normal, social responsibility, comfort, familiarity, to name but a few, which, when combined, tell us more about those acts and actions which make those with learning disabilities feel that they do not stand alone in the environments where they live and the surrounding communities.

As has been evidenced, community is an important social construct in the development of belonging for PWLD. These communities are often networks and connections of their own making, creating friendships and relationships with those in closest proximity, and further afield, which speaks to how those with learning disabilities see their own lives. Clubs and groups – especially ones shared with other PWLD – are clearly pivotal in the development of relationships and so

the current cuts and closures widespread across GG&C, and further afield, threaten to reduce social mobilities, potentially tightening opportunities for community involvement as opposed to expanding them. Counter to PWLD blending into society in a fashion of their own making, this roll-back arguably leads to reduced and unfulfilling social boundaries whereby those with learning disabilities feel truly that they are living (again) in the confines of an 'asylum without walls'.

Through the interactions experienced within community spaces, PWLD are building critical life-skills and, more than ever, it is crucial to think about the ways in which residential mobility and belonging for people with learning disabilities impact on learning such skills. Belonging involves a complex entanglement of different emotions and experiences for which there is no replacement for trial and error, further highlighting the importance of allowing risk to permeate the lives of PWLD; a topic which will be picked up again in Chapter 8.

Communities, and therefore lives, in which those with learning disability feel that they belong are those where they have the opportunity to create and rework the bonds and networks framing how they live and move, even if these networks are made within organised group settings. A learning disabled community is no less important than being a wider part of the non-learning disabled community; what matters is that decision-making and mobility allow the exploration of people and environments that matter to PWLD themselves and result in a sense of their belonging. Indeed, their lives will inevitably be an entanglement of learning disabled and non-learning disabled environments through which their 'everydays' are woven. It is thus crucial to residential mobility, and its success, that these-small scale and mundane experiential happenings complement larger-scale rethinking of where PWLD should and do live, therefore feeding into the policies which have greatest positive impact on this aspect of their lives.

Bringing the thesis to a conclusion, Chapter 8 leaves behind the empirical work of Chapter 5, Chapter 6 and Chapter 7 and instead brings together the main themes of the thesis. Here ideas of home, movement, belonging and decision-making are more obviously intertwined. This leads to a drawing out of key issues raised by the thesis and recommendations which could be put forth in order to give voice to differently-normal lives of PWLD (Hanson and Philo, 2007).

## Chapter 8

### Conclusion

As discussed in Chapter 3 and evidenced through the voices of the PWLD in Chapters 5,6 and 7, policy Frameworks in Scotland, namely *SAY?* (2000) and *TKTL*(2012), have undoubtedly changed the learning disabled residential landscape. These changes run in conjunction with UK wide austerity policy and a rolling out of neoliberal approaches (Power, 2013) which expand self-interest, calculability, competition, efficiency and profit into all areas of life, including welfare (Mladenov, 2015). What this thesis has sought to unearth is the complex relationship between large-scale policy frameworks and small-scale personal interactions of, at and around home, ones which afford PWLD the ability, or not, to make decisions about where they live. Foregrounded by the historical displacement of PWLD into institutional spaces, this work has attempted critically to evaluate a move out of 'the institution' and into the community, at the same time ensuring a sensitive co-production of knowledge about learning disabled lives which allows the voices and experiences of the 'abnormally normal' (Hansen and Philo, 2007) to be brought to the fore. In this way, much needed personal insight and texture has been added to the corpus of work which focuses on learning disability and home. As a space which is both material and discursive (Putnam, 1993), home is a location worthy of geographical attention (see Blunt and Dowling, 2006). Questioning the 'naturalness' of this space, Bowlby *et al* (1997:345) suggest that there is a need to "question, expose and isolate" the home-space, and so this project has queried what is known about the mundane, arguably ordinary lives of PWLD as they attempt to manoeuvre across and to negotiate their residential landscapes. As Hanson and Pratt (1988) and Brickell (1997:347) have argued, home represents a "sociospatial boundary" between the personal and other significant scales of organisation,

telling us more about the role of decision-making, belonging and movement of, and at, home, in the formation of knowledge about learning disabled lives which must be understood in the creation of policy which concerns them.

### ***Moving landscapes of learning disability***

This thesis has approached the residential mobility of PWLD from an intimate perspective, at all times bringing forth the sensitive wrenching real-life stories of those people for whom this subject is most keenly felt. The three main empirical chapters (5, 6 and 7) revolve, in detail, around the themes of decision-making, movement, belonging and home: consistently spiralling around how those themes march in lock-step throughout the observations offered by my learning disabled interviewees. Methodologically, I have quite deliberately worked with my core interviewee respondents in an in-depth way – their names and their words, or those of their carers, echo throughout these chapters; we meet them repeatedly, and so their stories do indeed become familiar. To an extent the approach taken here echoes that of humanistic geographer Rowles (1978), really getting close to the intimate grain of lives that are, on the outside at least, seemingly quite restrained and unexciting. This “quest for authenticity” is reminiscent of Rowles (1978:111) work with the elderly in the US which aims to present the “raw coherence” of their experience in the context of *their* socio-political landscape. Nonetheless, there is much to be learned from such an in-depth engagement with PWLD.

#### Decision-making

The art of decision-making is approached by Chapter 5, attempting to understand more clearly about how decisions are made and not-made by those with learning disabilities. Here, I deny that decision-making

is an innate quality for any person, rather recognising it as a process of learning to choose, access to which not all PWLD have. This experiential process – one in which mistakes are a key feature – can be seen throughout this chapter to push the boundaries of what PWLD are able to do and to say, and ultimately the changes which they are able to enact in their lives. The thin line between protectionism and infantilising requires a certain amount of ‘letting go’ by many of the parents and carers also interviewed; the positive impacts of less constraining access to decision-making opportunities made evident in both Wilma’s (23) large-scale decision to move out of the family home and Robert’s (34) small-scale decisions about his evening drink. In both of these cases, supported decision-making opportunities have led to greater self-awareness, growing the abilities of respondents to make decisions and boosting their confidence to express themselves. Many respondents did indeed report positive decision-making experiences in which they felt in control, not least Paul’s (62) experience of living in his own home for the first time. Crucially, Paul’s story also highlights the positive changes which can happen when decision-making is approached as an interactive practice.

Far from being belittled by input from others, I argue that decision-making in this way is in fact not dissimilar to how any of ‘us’ make decisions about our lives; ‘we’ too seek the opinions of important others and use them to frame our thinking. It stands to reason that PWLD do have opinions and concerns with regards to their homes (or any other facet of their lives) and as such it is important that conversations between PWLD and their significant others are opened up. Respondents within this study have shown that making decisions about home, among other things, is an empowering act and that conversely, a lack of decision-making opportunity is restrictive. Shutting down opportunities to make decisions impacts on feelings and experiences of independence, mobility and general wellbeing and

mental health. It is hence crucial that PWLD are consulted, listened to and appropriately communicated with about their homes and other topics of importance, not only by parents and carers – who I am sure are already aware of this need – but by local authorities and the government who must understand that home is an emotional, not merely a physical, space.

### *Movement*

Seeking better to understand learning disabled mobility of, in and around the home, Chapter 6 discusses the why, where and when of movement for PWLD. Most notably this chapter adds to the contention put forward by Andrews *et al* (2012) that residential location impacts greatly on learning disabled lives. Arbitrary placement of PWLD in communities which are not suited to their physical, mental or emotional needs reduces movement in local neighbourhood spaces as evidenced by Barbara's (48) growing isolation in her own home. As such, options for PWLD become limited, so closing down opportunities for making meaningful connections with the learning disabled and non-learning disabled communities in which they live. Again, this calls for an open dialogue with learning disabled individuals to ensure that an 'any home will do' mentality is not par for the course for access to local authority housing or housing association housing, in which many PWLD reside. By prioritising the financial benefits of certain housing options for PWLD, this ignores the physical and emotional needs of PWLD and so risks isolating PWLD in their own homes as much as they ever were when residing in 'the institutions' of old. Many respondents spoke of 'just getting out' and this phrase in itself captures movement as a social act. Oppositional to the neoliberal need for productive citizens in normal spaces, it must also be recognised that PWLD often require learning disabled-only spaces in which to learn and grow as individuals. As such, it is my feeling that any and all movement of PWLD, be that in learning

disabled-only spaces or not, must be a priority, allowing PWLD to interact, to make acquaintances, to discover new places and new opportunities, to create memories and to maintain friendships which truly lead to fulfilment. Moreover, movement of, at and around home increases visibility of PWLD as active citizens and, while potentially opening themselves up to further stigma and bullying, a chance can also be created to become known as more than 'just' learning disabled; as shown here by Mae's (50) charitable efforts for a cause close to her heart. Through movement, learning disabled lives are opened to the risky business of social interaction, reimagining the learning disabled body as visible in a way that debars the continuation of mainstream ignorance on the topic of learning disabled equality.

### Belonging

In its discussion of belonging, Chapter 7 draws attention to the importance of community for PWLD, recognising that ability of community ties to heighten feelings of belonging, as shown by the ties of friendship and solidarity between Barbara (48) and Maria (64), and their corresponding neighbours. The strong bonds created by living in close proximity were often seen to extend beyond kind offers of help, to neighbourly involvement in personally sensitive tasks such as that shown to Stuart (42) by the neighbour who helped him to read letters from his housing associations and manage his money. As mentioned already within this thesis these relationships are perhaps not any different to those experienced by close, non-learning disabled neighbours, but arguably these relationships are more important for PWLD who may expect to be mistreated, stigmatised, targeted or bullied. This adds weight to the claim that finding the correct residential setting for PWLD can have positive affects in all areas of learning disabled life. This point is strengthened by the noted negative impacts of Mike's (29) community setting on his mental health. The arguments presented here give further credence to my assertion that

learning disabled-only spaces have a place in the creation and development of belonging. Hall's (2004) states that the notion of simple integration of PWLD into non-learning disabled, 'mainstream' society is ignorant of structural and discriminatory practices faced by PWLD as they attempt to navigate non-learning disabled community spaces in which they are supposed automatically to belong. The barrier to belonging, then, is a strong political and social sense that PWLD *need* to integrate seamlessly into non-learning disabled society in order to be fulfilled. Instead, PWLD would be much better served by financial and personal support to create and maintain learning disabled-specific spaces which identify the need for PWLD to have the opportunity to learn self-awareness which may lead to a sense of belonging; this may or may not result in non-learning disabled community integration.

### ***Institutions and independency, risk and residency***

In Chapter 4, I questioned the assertion that PWLD are living in post-institutional spaces and I come back to this issue further to unpick this idea. Institutionalisation removed learning disabled bodies from society in a very literal sense, rendering those bodies invisible and unknowable (Hall and Kearns, 2001). Through a process of deinstitutionalisation, these bodies were brought out of their medically induced hiding places and into the public domain in search of a better, more dignified life. In 2005, however, Metzel termed the social and economic control and regulation of community-based funding and services tantamount to creating an "asylum without walls". Wolpert (1974), long before, had studied the 'ghettoisation' of the deinstitutionalised landscape for people with mental health problems. Peet (1975:568) noted that disadvantage, such as that experienced by PWLD even when in deinstitutional settings, constructed a "prison of space and resources" which imposed limitations in environment, mobility, and "quality of social resources"

(Dear, 1981:484). Written between 1974 and 2005, one might expect the deinstitutionalised landscape to be somewhat different contemporarily than as outlined in these examples, but, I would argue, this is not straightforwardly the case.

Hall and Kearns (2001) suggest that there is need for a deeper questioning of the processes of deinstitutionalisation, seeking to understand the binaries which have been erected between institution/deinstitutionalisation, isolation/integration and exclusion/inclusion. If, as *SAY?* (2000) and *TKTL* (2012) claim, deinstitutionalised spaces equate to a better quality of life, it must be questioned exactly how this process has influenced opportunities for decision-making, belonging and movement for PWLD at a number of spatial scales. As argued in Chapter 4, a key theme of community-based policy frameworks has been to popularise the notion of independence and control for PWLD over their own lives. Much like the poorly planned move out of 'the institution' the meaning of independence has become increasingly obscured and unclear. The idea that someone with learning disabilities should 'go it alone' is flawed for many reasons, not least because PWLD represent a group of people very rarely afforded the right of decision-making. This assertion is further problematised since it fails to recognise that autonomous decision-making for all adults – including those without learning disabilities – still requires input from the social and familial structures in which the decision is made; decisions are not made in vacuums. Ignoring decision-making as constituted by and affecting of the social, cultural and economic contexts framing subjective everyday interactions over-simplifies the complexities of making decisions about one's life and under-plays the dependencies which really make *all* lives (Hall and Wilton, 2016).

Here I once again return to Wolpert's (1980:397) paper on the dignity of risk, whereby he subverts the common tropes of decision-making

capacity by suggesting that the “the notion of competency results from a process of labelling rather than from any inherent differentiation”. It is already known that PWLD are a marginalised group and it would be remiss to suggest that all PWLD can make decisions with a full understanding of the outcomes, but in assuming that all PWLD are incompetent at all times, there is a failure to recognise and to learn from their lived experiences which could positively inform policy. Moreover, as I have argued at various points in the thesis, PWLD must be allowed to make mistakes; to choose the wrong home, trust the wrong person, burn themselves making a cup of tea. It is problematic at best, and ludicrous at my most emphatic, to suggest that those without learning disabilities can and do always make well-measured decisions which never result in messy outcomes. Wolpert (1980:400) points out that, without the ‘abnormal label’, ‘normal’ people enjoy a “cloak of competency to cover their inabilities and their failures” which skilfully glosses over the cluttered and intricate process of their own learning to make and to enact good decision-making (at least some of the time).

The risky business of choosing is further impeded by policies which continue to shrink opportunities for movement capable of increasing belonging and attachment. Continued decentralised care and support provision have resulted, and continue to impact on, the opportunities available to PWLD, increasingly reducing spheres of influence around and of home. Although home can be a space in which identities are created and expressed, home alone cannot provide the social exercises of being visible as an interacting learning disabled person in the community. Hence, the issue is so much more than just whether someone ostensibly lives independently – indeed, living independently can also mean living a lonely life doing little more than sitting around in a bedroom or front room. Conversely, living dependently, whether in a separate home, a family home, a group

home or even a residential institution, may be far more fulfilling. The secret is to avoid any simple binary with a simple 'good/bad' logic, which arguably continues to be the drift of many policy initiatives (well-meaning and in certain respects radical, in a 'social model' sense, as such initiatives might be).

Power (2008:835) has argued that deinstitutionalisation has created new entanglements of inclusion/exclusion within community spaces which involve the constant negotiation of the "socio-spatial fine print" of everyday life on the margins between learning disabled only spaces and 'mainstream' spaces. Picking up on points by Barnes *et al* (1994:74) on the role of the professional in interpreting disabled people's "socially valued roles and activities", I argue here that giving voice and opportunities for decision-making to PWLD, both in small scale decisions *at* home and larger scale decisions *about* home, begins to encourage and to grow a group of individuals who feel empowered and sure enough of their identity to make meaningful headways towards a life that they wish to lead; but not under the guise of personalisation. While I agree with the overarching approach of personalisation, its current form serves only to force the care burden back towards those with learning disabilities, asking them to fix problems which they have not been afforded the space to be involved in identifying.

#### *Home and learning disabled inclusion*

Taking Power's (2008) clash between care and dependency in a new direction, I wish to dismiss the terms 'inclusion' and 'exclusion' as prescriptive readings of where PWLD should live, socialise and work, or not, and instead champion a more fluid and truly inclusive understanding of being 'inside' and 'outside'. Learning disabled only spaces may be introverted, but it is also the case that these spaces are specifically designed to support and to encourage PWLD, growing

confidence and providing advocacy which seeps into other areas of life. Controversially perhaps, I argue that we must stop ignoring difference, instead recognising that humans are *just* all different. When the “cloak of normality” (Wolpert, 1980) drops from us all, we can begin to see that equality is a failing political carrot being continually dangled. This has been discussed in Chapter 3 in relation to the roll back of the welfare state in the provision of services and the supposed grass roots, independent support and care that these neo-liberal approaches were supposed to instil. Alternatively, PWLD need equity, a deep-rooted understanding enshrined in policy which recognises that PWLD, and those without, may need more or less support, more or less care and are more or less able to take part in all aspects of life. What I propose is indeed a dignity of difference whereby PWLD are encouraged to attend learning disabled only groups, stay in a group home or live with their parents, if that is what they want, simultaneously being made aware that other options exist and being provided with the appropriate support to make consequent decisions. This further attends to the call by Thomas (1999) and Reeve (2012) for support and care which recognises that PWLD need psycho-emotional support which begins to break down ‘barriers to being’ and well as ‘barriers to doing’. Until this scenario is realised, it is my belief that we cannot claim post-institutionalisation, not until policy is created for and by PWLD in a way which attends to the notion that PWLD are sometimes hindered by their learning disability but are always differently normal.

A strong stance has been taken throughout which recognises that the term ‘normal’ is not only utterly subjective, but also utterly useless as a descriptor. To be normal has been critiqued by Hansen and Philo (2007) who speak simply of ‘doing things differently’ and, in listening attentively to those for whom difference is assumed, this work has set out to fan these flames. It suits the rational mind to consider disability,

especially learning disability, as distinctly 'other' (Hall, 2004; 2005), but here I have attempted to destabilise the binaries between 'us' and 'them', using experiences of learning disabled residential mobility to frame ideas which, more often than not, attest to the fact that many PWLD are indeed 'the same as you'; quite definitely and without the need for the question mark.

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## Information Sheet for participants



# **The Moving Landscapes of Learning Disability: Residential Mobility and decision- making for people with learning disabilities**

### **Information for Participants**

My name is Victoria Smillie, and I am a PhD student from the University of Glasgow. I am inviting you take part in a research study. The following sheet is designed to give you more information about what the research involves. If you are interested in taking part we can discuss any questions you might have about the research.

### **Why is the study being done?**

Very little is known about where people with learning disabilities live at the moment or those places where they have lived in the past. Through this research project we would like to find out more about these places. We hope that it will make a difference to policy decisions for people with learning disabilities in the future. This study also forms the main part of my PhD project at the University of Glasgow.

### **What exactly are you trying to find out?**

We want to know more about where people with learning disabilities live now and in the past, and your feelings

about this. We also want to ask you who decides where you live and how decisions are made about where you live. You will be asked about your home and about the community in which you live. You will be asked about changes in policy which affect where you live. We will also be asking a member of your family or your carer these questions. It is important to the researcher that your story is heard. This will be done by taking part in a 1-1.5 hour interview between you and me. This interview can be split into several much shorter interviews if this suits you better.

### **Why have I been asked?**

You have already returned a questionnaire and said you would like to hear a bit more about the next stage of this study. Around 25 adults with learning disabilities and their family members/carers in the Greater Glasgow and Clyde area will be invited to take part in this stage of the research.

### **Do I have to take part?**

There are three parts to the research and you can choose to take part in all of them, none of them or some of them. You can choose if you want to take part in the research.

1. **Questionnaire:** you have already returned the questionnaire – thank you!
2. **Interview:** You can choose to take part in an interview about your home. You can say no to taking part in the interview at any time.
3. **Case-studies:** If you enjoyed the interview you can choose to make a case study of your homes by taking part in another interview with the researcher.

### **What will happen if I take part?**

You will be given the chance to ask as many questions as you like before you decide to take part. If you decide that you would like to take part, you will be asked to sign a consent form. Before the interview, you and I will have a brief “mini workshop” together with someone who supports you if you wish, to agree a date, time and place which suits you best for the interview, and whether to use pictures and photographs too. You are able to have someone with you at the interview. With your permission, the interview will be tape-recorded and I will take notes throughout. You are entitled to ask to see these at any point in the research process. During the interview I will ask you questions about the homes and neighbourhoods in which you have lived and how you felt about these places. If you choose to take part in an interview, or an interview and a case study, you will be asked to tell me stories about the places you have lived. Together with me you may be asked to draw pictures and maps of places you like to visit. If you wish to do so, you can also walk around your home or neighbourhood with the researcher, telling stories as you walk. After the interview and the case study, I will type out everything you have said and from this, will use parts of your answers in writing up a big report. This report, or an easy read summary, will be made available for you to read when it is finished.

### **What happens if I change my mind about taking part?**

You can choose to stop at any time, without having to explain yourself. It will not affect the care or support you or your relative receives in any way. If this happens you will have the option to remove all parts of your interview from the research and it will not be used in the reports.

### **What are the possible advantages and disadvantages of taking part?**

You will not be offered anything in return for your time. It is hoped that you will find the experience of participating

in a research study, enjoyable and empowering. The research is not meant to be upsetting and, if you find any questions distressing, the interview will be stopped immediately.

**What happens after the research finishes?**

After all interviews have been completed, the researcher will take parts from all interviews and include them in a final report. This report, or an easy read summary, will be available for you to read when the report is finished.

**If I take part in the study will other people know I have taken part?**

No. Everyone taking part in the research will be given a different name. You can choose your own name if you want to.

**Who is organising and funding the research?**

The sponsor, NHS greater Glasgow and Clyde is responsible for ensuring the research is properly organised. The research is funded by the University of Glasgow. The research team do not receive any personal payments for including you.

**Who has reviewed this study?**

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. This study has been checked and given...

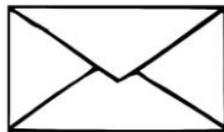
**Who can I contact if I would like more information?**

You may keep this information sheet, and if you take part, we will give you a copy of the signed consent form to keep.

If you would like to ask any other questions about the research, please contact me using the information below:



Victoria Smillie  
School of Geographical and Earth  
Sciences  
East Quadrangle  
University of Glasgow  
University Avenue  
G12 8QQ



07752479515



[v.smillie.1@research.gla.ac.uk](mailto:v.smillie.1@research.gla.ac.uk)

**Questionnaire**

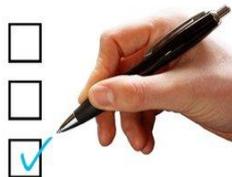


The Moving Landscapes of Learning Disability

QUESTIONNAIRE

This questionnaire asks you some questions about where you live just now and where you have lived in the past. You do not have to answer all questions if you do not want to. You can ask a parent, carer or friend to help you fill in the questionnaire.

1. How old are you?



Tick the box which describes you.

2. Are you Male or Female?



Male



Female

3. Who do you live with?

With my Parents

With Grandparents

With my Guardian

With friends

In a group home

With my partner

On my own

Do you want to tell me more about who you live with?

4. Have you ever lived in a Hospital?



Yes



No

Where was this Hospital? It is OK to say you do not know.

5. Have you ever lived in a group home with other people with learning disabilities?



Yes



No

Where was this group home? It is OK to say you do not know.

6. Have you ever lived in a care home (a residential nursing home where care and services are provided on site)?



**Yes**



**No**

Where was this care home? It is OK to say that you do not know.

7. Would you like to take part in interviews about your home and where you have lived? Please see the information sheet for more information.



**Yes**



**No**

If you would like to take part in more research about your home please fill in the box below.

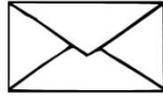
My name is:

My address is:

My phone number is:

**THANK YOU FOR FILLING OUT THIS  
QUESTIONNAIRE**

Please put the questionnaire in the stamped envelope provided and send it back to:



Victoria Smillie,  
School of Geographical and Earth  
Sciences,  
East Quadrangle,  
University of Glasgow,  
University Avenue,  
G12 8QQ

Please feel free to contact me with any questions  
you may have about any part of the research.



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## **Topic guide for Interviews with People with Learning Disabilities**

### **Opening**

Introduce myself and use the information sheets to talk through the design of the research and the part which would be played by the participant. Answer any questions which participants may have and ensure that they sign the appropriate consent form. I would ask the participant if they would like to use talking mats and if it would be helpful for them to be able to draw as we speak. I will let the participant know that they can change their mind about this at any point throughout the research.

The questionnaires will be used to select which questions the participant will be asked.

### **Parents home /with other relatives**

- How long have you lived with your parents/relatives?
- Who decided that you should live with your parents/relatives?
- What do you/did you like about living with your parents/relatives?
- What do you/did you dislike about living with your parents/relatives?
- What decisions do you/did you make yourself? For example do you/did you pick the activities you attend/ed?
- 

### **With friends**

- How long have you lived with friends?
- Did you decide that you should move in with friends?
- Do you decide where the house would be? If so, why did you want to live in this neighbourhood?
- What do you like about living with friends?
- What do you dislike about living with friends?
- Do you have regular help from carers and/or parents?

### **Group Home**

- How long have you lived in a group home?
- Who decided that a group home would be best for you?
- Did you help to choose the home?
- Why did you choose this home?
- What do you like about living in a group home?
- What do you dislike about living in a group home?
- Do you like living with other people who have learning disabilities too?

### **Care Home**

- How long have you lived in a care home?
- Who decided that a care home would be best for you?
- Did you help to choose the home?
- Why did you choose this home?
- What do you like about living in a care home?
- What do you dislike about living in a care home?

### **With my partner**

- How long have you lived with your partner?

- Who decided that you should move in with your partner?
- How did you choose the area you wanted to live in?
- What do you like about living with your partner?
- What do you not like about living with your partner?

### **On my own**

- How long have you lived on your own?
- Who decided that you should live on your own?
- Were your parents/relatives worried about you living alone?
- How did you choose the area that you wanted to live in?
- What do you like about living alone?
- What do you not like about living alone?
- Do you have regular help from parents/carers?
- If so, how do you feel about this?

### **Long stay hospital**

- How long did you live in a long-stay hospital?
- Who decided that you should live there?
- Did you like living there?
- What things did you like about living there?
- What things did you not like about living there?

### **Looking to the future**

- Who would you like to live with in the future?
- Where would you like to live?
- Why would you like to live there?
- Do you feel that you are being helped to make more decisions about your own life?
- Who helps you to make these decisions?

- Have policies such as 'The same as You' and 'The Keys to Life' changed the options for housing available to you?
- If so, in what ways?
- Have these policies allowed you to have more of a say in where you live?
- If so, in what ways?

### **Closing**

I would give the participant time to ask any questions about the interview or the research in general. I would then check that the participant understood what would happen now that the interview has been completed. Finally I would thank the participant for taking part and urge them to contact myself, my advisor or the sponsor should they have any issues or problems that they would like to discuss.

Scottish Institutions, 1913

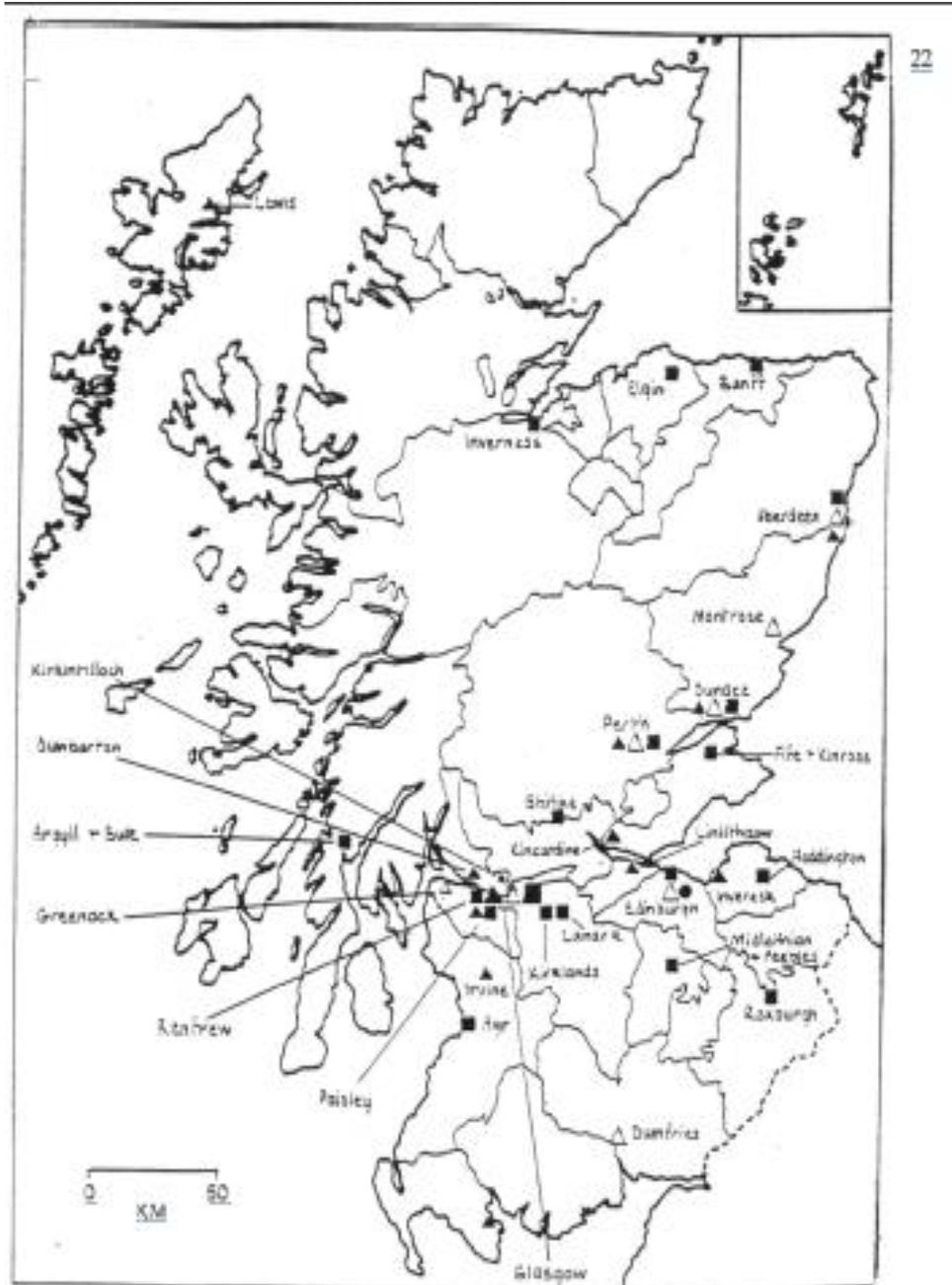


Figure 1.2 Map of institutional provision in Scotland, 1913<sup>1</sup>

- |                     |                                   |
|---------------------|-----------------------------------|
| △ Royal Asylums     | ● Private Madhouses               |
| ■ District Asylums  | ● District Madhouses              |
| ■ District Asylums  | ▲ Poorhouses with lunatic ward(s) |
| △ Parochial Asylums | ▲ Poorhouses with lunatic ward(s) |

<sup>1</sup> Source of data: GBCLS 15th AR (1913), *passim*. Map outline as for Figure 1.1. Institutions shown on the map have only been approximately located. It has not been possible to locate one poorhouse lunatic ward.





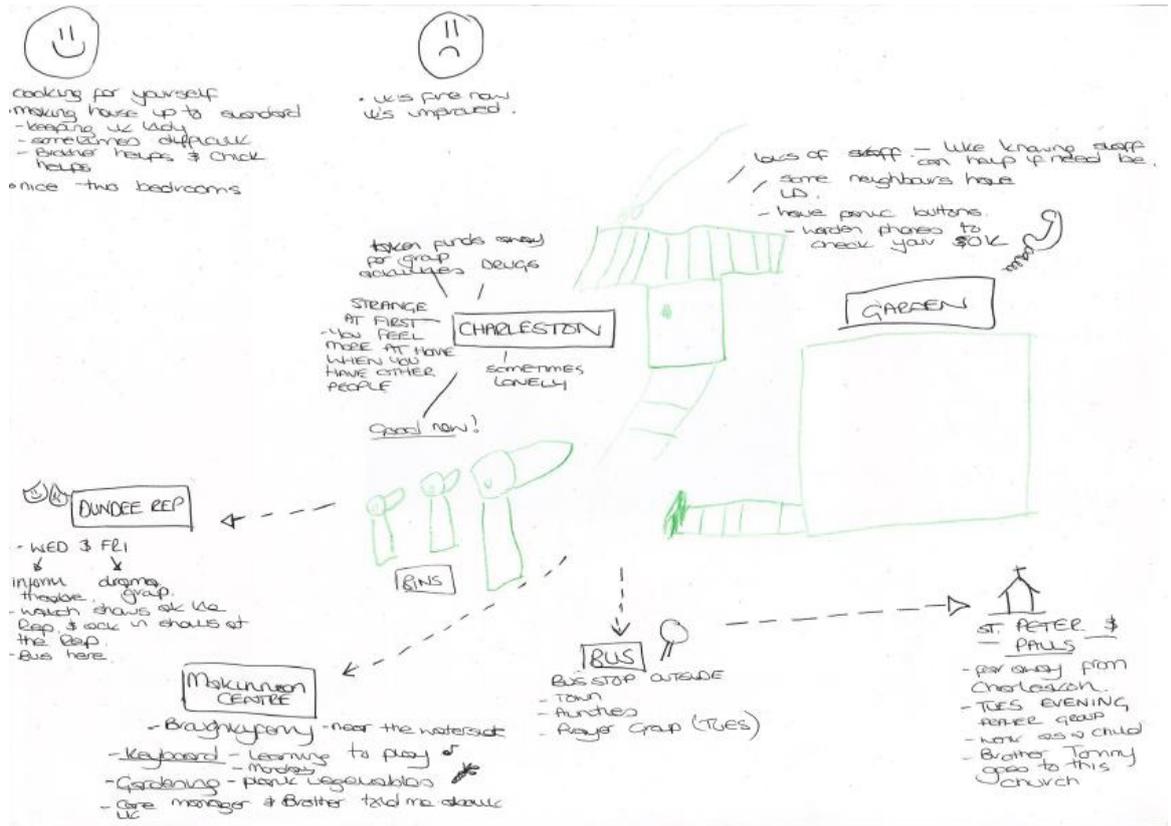






Appendix 10

Lawrence's case study: Charleston



Appendix 11

Lawrence's case study: timeline

