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LEEDS UNIVERSITY
THE SCHOOL OF SOCIOLOGY AND SOCIAL POLICY

**Exploring Quality of Life Changes and the Impact of a
Discharge Project for People with Learning Difficulties
Now Living in the Community:
A second evaluation**

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Abstract

This qualitative research is a second stage evaluation of a discharge process called the 'Towards 2010 Reprovision Project'. Eighty- six adults with learning difficulties were moved from a long stay hospital in Northamptonshire into independent living. A first evaluation (Topp, 2011) was commissioned to consider the processes, practices and initial outcomes of that project. Taking findings from the first evaluation, and using the social model of disability as a standpoint, this second evaluation research explored the lives of four of the people following discharge. This research asked:

1. What has changed in these adults lives now they have been discharged into the community?

2. What impact has the Towards 2010 Reprovision Project had on the quality of these people's lives?

The data identified two significant changes in the people's lives: change of environment and change of service provision. Impact on life quality was measured against themes evident in a literature search; independent living, establishing valued social roles, and being supported to become citizens. Using participant observation and semi-structured interviews with staff members currently supporting the individuals, these three themes were sought within the data gathered for this research. Nine specific indicators of life quality were also used to ascertain the impact of the Towards 2010 Reprovision Project on the people's daily

activities and experiences. These indicators were: continuity, choice and influence, status and respect, community presence, partnerships and relationships, competence, individuality, and wellbeing (Sterling, 2007; Clement and Rigby, 2010). Safety and security, highlighted as relevant to life quality within other literature (Hatton, et al., 2008; Personal and Social Services Research Unit, 2010; Tyson, et al., 2010), was also included as a domain within this study.

The impact of environmental changes on life quality was found to be highly positive. The impact of the change in service provision was sometimes found to be lacking in its implementation and therefore impacted less positively on the quality of some participants' lives. This supports Clement and Rigby (2010). This study recommends that service providers particularly consider staff recruitment and training issues to address this finding. The loss of a dedicated advocacy service also appears to be counter-productive to the participants' life quality. Further research on a larger scale is suggested.

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Chapter One: Introduction

Moving people with learning difficulties out of long stay hospitals is an international phenomenon described by Mansell (2005). This research project aimed to explore and evaluate the lives of four adults with learning difficulties following discharge from long term National Health Service care and accommodation to live independently in the community. It follows the completion of a joint healthcare and social care project called the 'Towards 2010 Re provision Project'. Known hereafter as the Re provision Project, its driver was the Valuing People (Department of Health, 2001) directive to close all long stay hospitals. This was part of the strategy to improve the lives of people with learning difficulties. The Re provision Project took nearly four years to complete. This was due to different understandings of the historical labels of learning difficulty and challenging behaviour, individuals' different communication needs, and individual's profound physical and sensory impairments. The project needed to be carefully managed according to current legislation (e.g. Mental Health Act, 1983; Human Rights Act, 1997; Mental Capacity Act, 2005), and, importantly, individuals' needs and preferences. The current research considers a small sample of the Re provision Project people to see what has changed for them, and how the project has impacted upon their life quality.

Background to this research

Disabled people's groups have been aiming for truly independent living for themselves since the 1980s (Evans, 2002). The disabled people's Independent Living Movement called for choice and control for all disabled people needing support to live independently as citizens (Ratzka, 2005).

Only 15% of adults with a learning disability have a secure, long term tenancy or own their own home – compared to over 70% of the general adult population who own their own home and nearly 30% who rent (Royal Mencap Society/Learning Disability Coalition, 2010).

The Disability Rights Commission stated in 2002 that independent living should be an enforceable right for all disabled people (Zarb, 2004), however, support for achieving independent living remains unevenly distributed within Great Britain. Disabled People have historically been excluded from making their own decisions (Campbell, 2004) but the rise of the self-advocacy movement (Goodley and Ramcharan, 2010) began to enable this for people with learning difficulties. Government directives now determine that all people with learning difficulties must be fully included in decision making (DoH, 2001; Inclusion Europe, 2008). To facilitate this, the Reprovision Project adopted the seven-step In Control method (Duffy 2003). This person-centred approach promotes choice for disabled people to ensure individual's needs are appropriately met. A

plan is agreed according to what type of support an individual needs and wants, and an Individual Budget (IB) is allocated. Having an IB means that money is spent by the recipient on care they choose, not on services imposed upon them. People receiving IBs are also eligible for other financial benefits. As hospital residents, the people involved in the Re provision Project received only the most basic income made up of Severe Disablement Allowance (SDA); some Disability Living Allowance (DLA); and possibly some Income Support. People living in hospital are not able to receive the care component of DLA and since July 1995 they may only receive lower rate DLA mobility component. Such a restriction effectively prevents people in long stay hospitals from applying for a Motability vehicle. Being part of the Re provision Project meant better access to public monies; essential to allow the people to live as independent citizens (Rioux, 2002).

As part of the Re provision Project, independent advocates, family members and familiar staff were brought together with individuals to form Circles of Support. These ensured that the decisions made were what individuals wanted, and, if capacity was lacking, were made, as far as could be reasonably established, in each person's best interests.

Decisions that needed to be made were, 'where are you going to live?' and 'who will provide your support?' The people would no longer be stigmatized (Goffman, 1963) patients, they would be 'ordinary' citizens with the right to live in ordinary housing; an option that had not

previously been available to them. Private homes were identified for everyone with the last person taking up their tenancy at the beginning of 2011. Support to live would no longer be given by Learning Disability Nurses; social care support workers would be provided instead.

Positioning myself

I have been an independent advocate for people with learning difficulties since 2007. I am also a disabled woman with Multiple Sclerosis who understands disability to be a socially constructed or created concept (Union of the Physically Impaired Against Segregation, 1975; Oliver, 1990a). Finkelstein stated that disability is caused by societal and environmental “disabling barriers” (1972:10). This includes subjection to the personal discrimination attitudes that often exist in Western society. Known broadly as the social model understanding of disability, it is in direct opposition to the medically-orientated perspective that positions disability from a faulty mind or body (Oliver, 1990a; 1996). Such a medical or individual model of understanding disability has historically been used to manage and identify people with impairments in Western society, particularly since Victorian times (Finkelstein, 1980).

As a wheelchair user, I have direct personal experience of physical barriers that create disability for people with physical impairments. I have also experienced being ignored and demeaned through the actions and attitudes of others. This latter experience often affects people labelled with ‘intellectual impairment’, ‘learning disability’, or ‘mental

retardation'. These labels have been applied to people who have collectively self-advocated to be known as People with Learning Difficulties (Goodley and Ramcharan, 2010). I use this descriptor throughout this research.

My experiences and knowledge of disability led me into my role as an advocate for adults with profound learning difficulties that lived within my local Healthcare Trust's Learning Disability Residential Service.

Advocacy support for this group of people was less about the removal of physical challenges, although many also faced these. The support that these people required was more about becoming empowered as individual people (Oliver, 1993). They needed to be shown, and supported to consider themselves, as valuable human beings; a concept that has often been denied them by 'others'. These 'others' should similarly be educated to understand people with learning difficulties as 'normal'. (For a broader discussion on the complexity of 'normality' see Talbot, Astbury, and Mason (2009).

My advocacy role was to support people to live their lives as independently as possible, without denying them their differences. This included helping them to understand what was being said to them, how to choose, and how to take control of their lives. It was also about enabling them to be included in everyday life and to be considered by themselves and others as 'normal' citizens (Ratzka, 2005). Facilitating this within a medically orientated institution was often challenging;

nevertheless, staff were encouraged to understand that all people have the same basic human rights to a quality life. This included asserting that even people who are totally dependent on other people for every aspect of their care and support should still be enabled to make their own choices wherever possible. My advocacy skills and beliefs led the way I conducted this current research, which is based on the normalisation principle:

... making available to all mentally retarded people patterns of life and conditions of everyday living which are as close possible to the regular circumstances and ways of life and society
(Nirje,1980:33).

The knowledge I gained through working with the people in the Re provision Project, and the findings of an initial evaluation I undertook of this Project (Topp, 2011), also guided my approach. I outline this evaluation in the following section.

An initial evaluation of the Re provision Project's processes and outcomes

As the Re provision Project neared completion for the majority of the people towards the end of 2010, an initial evaluation was commissioned (Topp, 2011). This highlighted the strengths and weaknesses of the practices and processes used by the Re provision Team. When evaluating the outcomes however, although the trend appeared generally positive for the former patients, only a limited amount of

evidence could be gathered. As Clement and Rigby state, “outcomes do not just ‘happen’, but are a consequence of what people do” (2010: 32). Many people were still either moving home or settling in with their new support teams; therefore much was still to be done. A recommendation made, therefore, was that a second study should be undertaken. This would consider the established outcomes for the people involved, particularly in relation to their quality of life. Furthermore, due to the timescales I had to work within when undertaking the first evaluation, I was unable to develop a method that supported the people themselves to be participants. All people should be given the opportunity to be meaningfully involved in research concerning them (Emerson, 1985; Kiernan, 1999; Kellett and Nind, 2001) yet achieving this with people who have little communication support is not easy (Tuffrey-Wijne, Bernal, and Hollins, 2008). This current research project forms that second evaluation and endeavours to be as grounded as possible in the direct experiences of the people involved. Although the thoughts and opinions of others, such as staff and families, needed to be included in my data generation, the findings are much less dependent on their opinions than they were in the first evaluation.

My research questions

In the current evaluation I addressed two fundamental research questions:

1. What has changed in these adults lives now they have been discharged into the community?

2. What impact has the Re provision Project had on the quality of these people's lives?

I aimed to address these questions by spending time with each person to find out what they were doing, how they were being supported to live their lives, and what plans were being made with and for them. I also aimed to consider the differences in the people's lives since they had moved out of hospital and the impact of the move on their current quality of life. To analyse the material gathered I needed to be reflexive (Alvesson and Skoldberg, 2000) if the individuals' opinions and feelings were to be interpreted appropriately.

As an evaluation, this research seeks to amass a "collection of information about the activities, characteristics and outcomes" (Patton, 1990:15) using different criteria. These criteria are considered as quality of life (QoL) indicators. An evaluation must have a purpose (Patton, 1990), therefore, the findings will be offered to the service providers for appropriate adaptation of services (Skea, 2008). The impact of the findings will also be available to planners of other Re provision Projects for people with learning difficulties, the local social services commissioners, the Learning Disability Partnership Board, and other interested stakeholders to raise awareness of the issues identified.

To conclude this chapter I outline the contents of the remainder of this dissertation. Chapter Two draws out the criteria identified as important to this evaluation and why these have been selected. It also looks at relevant literature in the field to identify themes and issues for analysis. Chapter Three describes the methods used to generate and analyse data, including why these were selected. Also identified are the challenges that could have occurred and those that actually did. The strategies used for establishing rigour within the interpretations and conclusions made are similarly identified, as are ethical considerations. The research findings are discussed in Chapters Four and Five. Chapter Four sets out findings around environmental changes and the impacts identified, whilst Chapter Five documents the changes of, and impact effects due to, the new service provisions. Chapter Six considers the strengths and weaknesses of this study and offers a conclusion.

Chapter Two: Understanding 'Quality of Life' and Defining the Evaluation Criteria

Disability' has traditionally been defined, organised and provided for by non-disabled people (Davis, 1990; Campbell, 2004). Disabled people historically experienced fundamental denial of the rights to be respected as individual citizens, as negative assumptions and expectations were often attributed to them by non-disabled people. Disabled people themselves began to campaign heavily for rights, choice and control in the early 1970s. Further broad yet deep overviews of works demonstrating this can be found in Albrecht, Seelman, and Bury (2001). Despite the advent of the social model understanding of disability (UPIAS, 1975) disability may yet remain to many as a question of individual 'normality' (Abberley, 1993) and assumed dependence (Oliver, 1993; Shakespeare, 2006).

For people labelled as having learning difficulties, history "has not always been a pleasant one and nor have their life experiences" (Grant, et al., 2010:3). Nevertheless, the labels known today only became established in the late nineteenth century (McClimens and Richardson 2010). Asylums built during the industrialisation age provided homes for those who could not work and had no family to look after them. As notions of insanity abounded, and social order was felt under threat, a medicalised, institutional approach to care and control became established (Scull, 1979). Wolfensberger (1975) offers four phases of institutional care. First, the 'deviant' is made 'undeviant'; then 'the

deviant' was protected from society; thirdly, society was protected by 'the deviant' and finally a 'loss of rationale' existed. The people in the Reprovision Project were discharged from a hospital built in 1968 that reflects these phases. A document from the time states that the hospital was:

...Purpose built for the care of people who were mentally subnormal. The layout and design have been so planned that the hospital forms part of the surrounding community and will not be an isolated unit...

The patients will lead as normal a life as possible in a hospital which is similar to that of a village community, providing all of the social, recreational and working needs, arranged around a centre. Here also are the chapel, shops, café, school, gymnasium, hydrotherapy pool and a unit for treatment and research. Sheltered workshops are located near the centre, but located some distance from the patients' living quarters, giving the patients a sense of 'going to work', which is a step towards normal living.

(Stillman and Eastwick-Field; Arschavir, A L, undated)

In 1952 more than 80,000 people with learning difficulties in the UK lived in institutions. By 1976 this had dropped to 50,000, with 4000 remaining 25 years later (Emerson and Ramcharan, 2010). The self-advocacy movement for people with learning difficulties (Goodley and Ramcharan, 2010) enabled people with learning difficulties to say what they wanted;

however, it was not until 2001 that the British Government listened.

Closure of all residential 'learning disability' hospitals was finally called for (DoH, 2001). The Reprovision Project meant closing the last 'learning disability' hospital in Northamptonshire, however, in 2008 528 adults still remained resident in a residential or nursing care home within the county (Town, 2010).

Understanding 'Quality of Life'

A literature search on quality of life (QoL) suggests that research into this area has been effusive, yet its definition and understanding remain elusive. Felce and Perry (1995) explore the definition and consider QoL measurement. They show the diversity of definitions and dimensions that have been proposed and highlight how early studies' criteria for life quality focused on activities of daily living (e.g. Tizard, 1964). These are essentially evaluations of rehabilitation techniques rather than studies of individual life quality (Felce and Perry, 1995). The term 'quality of life' may be universal and abound with principles of equality, yet a precise definition does not exist. (Felce, 1997).

Latterly, Montisci and Grant (2010) note that QoL is dependent on context. They cite Schalock and Felce's suggestion that QoL is "a multi-dimensional construct" (2004: 73) used in different ways. Understanding QoL differently allows for models to be proposed. Montisci and Grant (2010) cite the models of Felce and Perry (1996), Bach and Rioux (1996) and Renwick and Brown (1996) as examples. These, like other

models, continue to be tested and developed. The newest QoL model being used in the social care arena is the Adult Social Care Outcome Tool (ASCOT) (PSSRU, 2010). The breadth of these works shows that QoL is a constantly shifting and changing element for everybody. A person's location, the services available, other people's attitudes and actions, financial situations, past experiences and future anticipations are all involved; every circumstance that affects any individual at any one time will be relevant to determining their quality of life (Brown and Brown 2003).

Trying to define categorically what should make up a person's lifestyle for it to be of quality also remains elusive. Walmsley (2001) points out that a state of perceived luxury must not be assumed. She states that when looking to achieve QoL, normalisation can be a "yardstick" (p. 193) for evaluating the planning and delivery of services that are provided or offered. By this she means that a standard or dimension that is considered to be culturally normal, and which may be taken for granted by much of the population, whether they would choose it or not, may be something that people with learning difficulties want, and have the right to aspire and achieve. Having a quality life might then be perceived as having a 'normal' life according to the culture in which the person resides.

I acknowledge that this way of understanding QoL presents the non-disabled way of life as the 'norm' that does not consider 'difference',

either between or within impairment types, or understandings of disability (Marks, 1999; Shakespeare, 2006). Space does not allow a discussion here of the politics of difference within disability; for the purpose of this current research the pertinent point is, as it was for Skea (2008), about access to the standards of living that non-disabled people take for granted. I explore next three broad themes apparent in the literature on life quality for people with learning difficulties. **Independent Living, Establishing Valued Social roles and Becoming a citizen.**

Independent living

The type of life quality that has been specifically afforded people with learning difficulties has been researched since the 1960s. McClimens and Richardson (2010) cite research during the late 60s and 70s (e.g. Edgerton, 1967; Hunt, 1967; Edgerton and Bercovici, 1976) that found people with learning difficulties preferred to live in similar ways to those valued by other people. Findings were backed up by further research during the 1980s and 90s (e.g. Passfield, 1983; Heal and Chadsey-Rush, 1985; Booth, Simons, and Booth, 1990). These increasingly showed that living independently would improve the quality of life for people with learning difficulties. Reports by Poll, *et al* (2006), Hatton, *et al* (2008), Tyson *et al* (2010) further support this.

Attaining independent living has been disabled people's prime objective since the 1970s. It "is about disabled people having the same level of

choice, control and freedom in their daily lives as any other person” (Office for Disability Issues, HM Government, 2011). Evans (2002a) defines it as the ability to decide and choose what a person wants, where to live and how, what to do, and how to set about doing it. Davis (1996) offers ‘seven needs’ for independent living:

- Information
- Counselling
- Housing
- Technical aids
- Personal assistance
- Transport
- Access

Evans (2002a) notes the confusion disabled people experience around independent living is due to different systems used by different Councils.

Even he (Evans J. , 2002b) narrows the essential needs to five:

- Housing
- Personal Assistance
- Transport and mobility
- Access
- Peer Counselling and peer support

yet acknowledges that some Centres for Independent Living (CIL) include additional principles. Evans (2002a and b), like Zarb (2004), also asserts that a civil rights line should be taken for independent living. This

would ensure avoidance of dependency, segregation and discrimination, and support of a good quality of life (Oliver, 1990a). In relation to people with learning difficulties Valuing People (DoH, 2001) states that a 'whole life approach' should be envisaged, including those with the most profound impairments. Independent living must be at the heart of the approach with appropriate information and support available to support the rights of those people.

Independent living should support be underpinned by an ethos of choice and control, however, for this to happen services would need to be provided differently (Emerson and Ramcharan, 2010). Montisci and Grant (2010) agree that the planning, design and delivery of service provision should support the people with learning difficulties to achieve a quality of life that is comparable to other citizens. This further reflects the concept of normalisation described by Nirje (1980) in Chapter One.

Further to this, Wolfensberger and Tullman propose:

Normalisation implies, as much as possible, the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people (1989:131).

Quality of life is therefore not only about living in a normal home it is about having normal things to do, and be, within a society. It is also about being able to access the services and activities available to everyone else in society – and having the right to choose (even if you decide not to use them). As the people planned for their discharge,

appropriate roles and services needed to be identified that would enhance their life quality through independent living.

Establishing valued social roles

A great challenge within the Reprovision Project plan was to find socially-valued roles (Wolfensberger and Tullman, 1989) for the people following discharge; where were they going to go and what were they going to do to be 'normal' citizens? Disabled people have continually found multiple barriers to achieve valued roles as discrimination is met within education, employment, parenting, transport and other aspects of social life (Barnes and Mercer, 2004). This reflects Oliver's identification of disability as a social-relational construct:

The disadvantage or social restriction of activity caused by a contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from the mainstream of social activities (1996: 22).

Adults with learning difficulties have historically been condemned to long-term dependency and isolation (Grant, *et al.*, 2010) and although these authors note that progress has been made, there remains much to do.

Within the Reprovision Project, Circles of Support used 'blue sky' thinking to consider broadly and deeply what the individuals might achieve. Much support, planning and input from professionals was applied to this process. At the time, however, few relevant and

appropriate support and services existed that the people could use or access. One or two had the capability to be supported into paid or voluntary employment yet no support had ever been previously provided to attempt this. Additionally, involvement in daily chores, such as cleaning, shopping and cooking was poor. The roles and activities the majority of the people in the Reprovision Project had were mainly passive ones in front of a television. There were some walks and a few cinema trips provided by staff and the Healthcare Trust's peripatetic in-house service that visited once or twice per week. Some residents had day centre placements provided by Adult Social Care. Neither of these 'external' options could or would be continued in the same way following completion of the Reprovision Project.

The 'Putting People First' paper (DoH, 2007) called for traditional day services in out of town centres to be closed down. Around the time of the moves being planned localised personalised services were only just starting to be set up. This meant that as the residents of the NHS residential homes began to be discharged, few had established activities outside of an institution. Some day-opportunity activities have now begun (see Northamptonshire County Council's website [Northamptonshire County Council, 2010]) and more privately run opportunities are beginning to develop. The provision of more Changing Places (Mencap, 2009) also continues in local public areas. This campaign provides appropriate community toilet facilities so disabled

people can access more community presence and participation. Having individual support workers should facilitate better involvement opportunities. This current evaluation explores what constitutes and facilitates the people's valued social roles to determine whether a better quality of life is lived than that which they had prior to discharge.

Becoming a citizen

Citizenship is another term that is important to disabled people yet has no universal definition (Rioux, 2002). Rioux offers what she calls "a dynamic relationship along three complementary dimensions: rights and responsibilities, access and belonging" (2002: 216). These three dimensions are complex and some wider discussion is offered by Rioux (2002) and others (Abberley, 2002; Hahn, 2002; Roulstone, 2004; Zarb, 2004). Hughes (2002) demonstrates how citizenship has been based on a concept that it exists only for the non-disabled body; the 'faulty' disabled body is limited in its ability to be a citizen and can only accept charity or welfare. Rioux (2002) and Zarb (2004) make the point that citizenship is about equality, yet few guarantees exist about what might be provided equally, particularly when an individual lacks the support to exercise those rights. Disabled people, it seems, are historically understood to be disentitled to citizenship; there may be some rights to services but, like independent living, not to citizenship.

Achieving citizenship was the purpose of Duffy's (2003) In Control method. According to the principles of citizenship, people with learning

difficulties should have the same privileges and responsibilities as all other people in Britain and must be supported appropriately to achieve these. Duffy offered 'six keys to citizenship': Self-determination, Direction, Money, Home, Support, Community Life (Duffy, 2003). These are said to be universally applicable. They should be used to ensure service design promotes independent living and attainment of valued social roles. The evaluation of citizenship is sought throughout this research, as it is understood to be a major contributor to life quality. The three themes set out above appear necessary for the lives of all disabled people, including those with learning difficulties, to be of quality. They are sought within the data gathered with the participants. The next section determines the criteria used for specifically evaluating individual's QoL in their daily situations.

Determining the evaluation criteria: The Watching Brief

Throughout the Reprovision Project's discharge process the Watching Brief (Sterling, 2007) advocacy tool was used to support decision making, as the majority of people were deemed to lack capacity to make many decisions. For any issue or topic where a decision needed to be made on behalf of a person believed to lack capacity, a positive and negative assessment of that issue or topic would be weighed against different criteria, or domains. The Watching Brief states that eight domains make up a quality life: **continuity, choice and influence, status and respect, community presence, partnerships and**

relationships, competence, individuality, and wellbeing. This tool is underpinned by the principles of inclusion and control. If the decision needs to be made on behalf of someone that lacks capacity it should always be made in the best interest of the person based on what is known about that person's preferences and beliefs. The Watching Brief has rigour as the domains reflect 'five key accomplishments' for people with learning difficulties: Community Presence, Choice, Competence, Respect, and Community Presentation offered by O'Brien (1987), O'Brien and Lyle O'Brien (1991), and Clement and Rigby (2010). This chapter continues by exploring some of the wider literature around these domains, which can be evaluated both subjectively and objectively (Skea, 2008), to see whether or not they are necessary and sufficient criteria for this evaluation.

Continuity, Choice and Influence

These criteria can be said to be foundational to the Human Rights Act (1988). *Continuity* and *choice* are also fundamental to In Control (Duffy 2003). *Continuity* refers to people having a past, a present and a future; these should all be maintained within the whole life approach to care (DoH, 2001). *Choice* is reported on in all three In Control reports (Poll, *et al.*, 2006; Hatton, *et al.*, 2008; Tyson, *et al.*, 2010). Having real *choice* has long been highlighted as missing for people with learning difficulties (Collins, 1996) and Valuing People (DoH, 2001; 2009) highlighted this as a key principal of support. Sterling (2007) positions *influence* alongside

choice; suggesting that influence is seeing 'self-determination' in action. Self-determination may be identified as control by the individual, or self-advocacy, and reflects one of Duffy's (2003) six keys to citizenship.

Individuality

Not to be confused with the individual model of disability (Oliver, 1990b) *individuality* is closely aligned to self-determination. This implies that a person is not just part of a group known by a medical or social label but has an identity with unique gifts and skills. Putting People First (DoH, 2007) and Valuing People Now (DoH, 2009) both advocate personalisation of services for individuals. Brewster and Ramcharan (2010) explore the concepts of person-centred planning (PCP) and its forerunner, individual programme planning (IPP). Compared across five dimensions PCP is seen to be far more focused on the involvement of the individual. Whether the plans adequately reflect participants' individualities to provide and develop life quality is explored in the data.

Status and Respect

All individuals must be afforded *status and respect* in every aspect of life by others (Human Rights Act 1998). The need for a high-level of personal care has historically been known to leave disabled people with poor experiences of respect due to poor support of their dignity (Taylor, *et al.*, 2007). A report suggests 60% of adults with learning disabilities have been found to have experienced abuse at some point in their lives (Ann Craft Trust, 2010-2011). The recent exposure of the treatment of

adults at Winterbourne View Hospital further highlights the vulnerability of people with Learning Difficulties and Autism (Pitt, 2011). A recent appeal for breach of dignity was dismissed on the grounds of semantics when continence pads rather than support to use a commode during the night was deemed acceptable (Smith and Chambers, 2011). An appeal citing the Disability Discrimination Act (1995) was also dismissed with judgement suggesting financial considerations take precedence (Smith and Chambers, 2011). Observations of individuals' status and respect are highly pertinent to this evaluation.

Community presence

The need to establish and engage in communities of interest is explored by Ramcharan and Richardson (2010). They cite Seebohm in his recognition that community is not just about locality:

The notion of a community implies the existence of a network of reciprocal social relationships (1968: 147).

This network may be mostly outside the home and must be accessible to people who use mobility aids. Historically, community presence meant going to the traditional day centre that offered only passive 'warehouse' care (Barnes, 2003). Community presence will also occur within the home as individuals receive visitors. The previous discussion in the **establishing valued social roles** section suggests that local opportunities in the community may be improving. Exploring the opportunities the participants are being offered and supported to access,

both inside and outside the home, forms an important part of the current evaluation project. Further to Seebohm (1968), Nunkoosing and John add:

Community life revolves around a person's network of social relationships which afford the person opportunities to develop social roles as friends and companions (1997:10).

The next criterion explores understandings around this social role.

Partnerships and Relationships

As social beings, partnerships and relationships may be understood to be fundamentally important to all people. The second In Control Report (Hatton, *et al.*, 2008) included *Relationships* as an evaluation criterion, however it was not used in the first (Poll, *et al.*, 2006). The third (Tyson, *et al.*, 2010) uses the term 'being with people you want'. This development recognises the importance of this criterion. In line with the *continuity* domain, the current research aimed to see how the people's relationships with people they used to live with have been maintained since they moved, and how new relationships are being encouraged. Sterling (2007) includes *Partnerships* within this domain to allow for recognition of professional and working relationships. These are also important to consider when evaluating the impact on the people from the Reprovision Project.

Forming relationships is considered one of five key accomplishments in a person's life (O'Brien, 1987; O'Brien and Lyle O'Brien, 1991). Forming

relationships is, however, particularly challenging when opportunities to meet people, share, contribute and interact, are lacking (Hogg, 1998; Whitehouse, *et al.*, 2001). The implication is that meaningful interactions with others should be sought on behalf of the people with learning difficulties and maintained by others where necessary (Sterling, 2007). This should include sexual relationships where appropriate (Evans and Rodgers, 2000). Appropriate physical and emotional support is imperative to enable the opportunities that do arise to be successful (Nunkoosing and John, 1997). These, and methods for organising transport, and actively seeking opportunities are also explored within the data.

Competences

It is not the quality of tasks we can perform without assistance that matters but the quality of life we can lead with help. To retain the old physical criteria of independence only contributes to the very isolation we seek to avoid (Crewe and Zola, 1987:347).

Sterling (2007) identifies *competences* to broadly cover all aspects of skill availability. All skills should be supported to be maintained and developed to enable an individual to be empowered and thereby take control. Within this domain I specifically identify communication.

Communication does not appear in any of the 'In Control' evaluations and according to Martin, *et al.* (2010) there is an apparent dearth of literature on nursing people with learning difficulties and non-verbal-

communication. Hogg (1998), however, notes the importance of communication skills for establishing relationships. Samuel, *et al.* (2008) also suggest that enhancing communication skills with people with profound learning difficulties may have a positive impact on relationships and social skills. Communication is also highly important for achieving daily living skills (Shessel and Reif, 1999) and accessing public services (Abraham, 2009). Communication is therefore fundamental to life quality.

Wellbeing

This domain encompasses physical, psychological, and spiritual health. Hatton, *et al.* (2008) and Tyson, *et al.* (2010) identify health and well-being as an important criterion to be measured when evaluating outcomes, and this is echoed by Michaels (2008). Many forms of learning difficulty are known to be exacerbated by secondary health impairments, such as epilepsy, poor nutritional intake, digestion and elimination, heart problems and respiratory difficulties (Kerr, *et al.*, 2003). People with learning difficulties are also of course subject to the same ailments as people without learning difficulties. Changing the GP may affect how people with learning difficulties are able to engage with primary care services and consequently any necessary secondary care treatment. *Death by Indifference* (Mencap, 2007) and *Six Lives* (Abraham 2009) demonstrate how poor secondary care has been for people who are unable to communicate and are unbefriended. Effective diagnoses, monitoring, and treatment of short term or chronic illness

must be ensured to maintain individual well-being (Mackenzie and McAllister, 2010). Spiritual wellbeing was previously provided by the Healthcare Trust's chaplaincy service and the outcome of losing this service is explored within the findings alongside the other health and well-being criteria specified here.

Safety and security

Although comprehensive, The Watching Brief does not identify safety and security as a discreet essential domain for a quality life. This area is nevertheless used by Hatton, *et al.* (2008) and Tyson, *et al.* (2010). The criterion is also identified within other impact tools that explore QoL for older and disabled people, such as ASCOT(PSSRU, 2010). Cocks and Broaden (2010) identify safeguarding as an attribute of planning a personalised life that emphasises positive outcomes whilst addressing areas of risk. The previously stated example of Winterbourne View (Pitt, 2011) shows the importance of appropriate procedures and safeguarding of vulnerable adults. Safety and security is also related to the location of the home, and how participants are supported to move around in the home.

Summary

This chapter explored the literature on quality of life and found that there are no absolutes; quality of life is affected by circumstances, which are both fluid and contextual. All activities and experiences offered should be

acceptable for the local population (even if they might not choose to do them), and take place in environments where any person may wish to go. Three themes were identified as a basis for achieving quality of life: **Independent living**, where people have choice and control over where they live and who they live with; **valued social roles**, which must be established with appropriate support to enable people to **become citizens**. These three themes and nine specific indicators provide important QoL findings for the current evaluation. In the next chapter I set out the methods I chose for the current research.

Chapter Three: A Social Model Approach to Qualitative Disability Research

This chapter sets out my research approach including how I aimed to manage data collection and analysis. I also include here a section on methodological dilemmas and how I reconciled these. As a final section I consider and reflect on whether my research process and practice was ethically challenged in any way.

The disabled people's movement (Davis, 1996) calls for the inclusion of disabled people in everything that happens in their lives. This includes full involvement in any research that affects them directly (Zarb, 1992; Ward and Simons, 1998; Walmsley and Johnson, 2003). Ideally this would be to the point of setting the agenda and controlling the entire research production and dissemination. Furthermore, disability research must aim to make a difference to the disabled people being researched (Finkelstein, 1999). Such research is identified as emancipatory, which Barnes defines as:

...the systematic demystification of the structures and processes which create disability and the establishment of a workable 'dialogue' between the research community and the disabled people in order to facilitate the latter's empowerment (1992:122).

The importance of the inclusion of people with learning difficulties in research practice has been discussed extensively within academia (For example; Stalker, 1998; Chappell, 2000; Walmsley and Johnson, 2003; Nind, 2008). These authors recognise the immense challenges of

undertaking full emancipatory research with people with learning difficulties. However, if research cannot be emancipatory then it can at least aim to be by supporting participation appropriately (Zarb, 1992). Evaluation research has proliferated since the 1960s. Smith (1999) notes that different classification types were apparent in the 1970s, integrative strategies in the 1980s, and meta- theories in the 1990s. Critiques on a number of levels have been offered, with problems associated with method-orientated evaluations identified by Chen and Rossi (1992). These authors highlight the current neglect of programme theory, which leads to “black box evaluations” (1992:18). This only identifies inputs and outputs rather than causes. Fetterman’s (1994) ‘empowerment evaluation’ promoted ownership of the findings by those involved in the practice or process being evaluated, however, Smith (1999) points out that ‘empowerment evaluation’ may still not be empowering evaluation. Acknowledging these comments, the calls for emancipatory social model research, and recognising the challenges of including people with learning difficulties fully in this research, I undertook a collaborative (Lincoln and Guba, 1985) participatory approach. The participants were not included in the analysis process; however, time and appropriate support were given to support participation.

My approach

I adopt a critical ethnographic approach to this social evaluation looking at people and the world they inhabit. Ethnography is described as a “people-method” (Smith, 1998:165), or, “literally, ‘writing about people’” (Goldbart and Hustler, 2005:16). Ethnography aims to determine meanings, including the bases people use to make sense of their world. The critical aspect reflects the boundaries of power and resources open to the people on which this research focuses (Hammersley, 1992). The research is empirical as it “collects data about people and their social contexts” (Somekh, *et al.*, 2005:1) to test or generate social science theories. I use the social model of disability (Oliver, 1990) as my basis of enquiry.

Data was generated and analysed using qualitative methods. Qualitative research aims to find clearly identifiable evidence to make sense of people’s meanings (Silverman, 1993) using an appropriate form of communication. It may also be broadly defined as:

...any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification (Strauss and Corbin, 1990:17).

Viable research methods within the learning difficulty arena have been and continue to be developed to enable clear interpretation, analysis, and robust findings to be made (Nind, 2008). The fundamental basis of whichever method or approach is used depends on the ontology, or

question of reality, and the type of research question posed (Blaikie, 1993). 'What' questions are asked to explore and describe social lives (Blaikie, 1993) and the answers are interpreted. Interpretation is of great relevance when communication skills are limited; furthermore, no one can know precisely what another thinks and feels (Denzin, 1998).

Sampling

I used purposive sampling (Patton, 1990), as individuals were selected according to specific criteria. Due to the limited time available, and the challenges of my own impairment and paid work, these criteria were severely restricted. I wanted to select participants that had been discharged in to their new homes with a new support team for as long a time as possible. This attempted to allow for any settling-in challenges to be resolved. I only considered individuals with whom I had previously worked as their advocate to allow for relationship forming. All participants were also to be supported by the same provider, thus preventing differences in company policies and procedures from impacting on the findings. A potential purposive sample of eight people was identified with my intention being of working with no more than four. The drawback with this sampling choice is that the research is very narrow in the information gathered and analysed; a greater range of differences would suit a larger evaluation.

Potential participants and their circles of support were sent letters explaining my research proposal and asking for interest in involvement

(Appendices A and B). Once my sample was established I gave each person further opportunity to decline participation at the beginning of each meeting. On completion each received a letter of thanks (Appendix C).

Meet the participants

Two women and two men participated in this research. The following table outlines relevant characteristics.

Name* and gender	age	Specific diagnosis	New living arrangements	Time living in full time institutional care
Richard (M)	47	Apert's Syndrome	Shares with Clive and Annabel	Since birth
Clive (M)	57	Down's Syndrome	Shares with Richard and Annabel	Since childhood
Annabel (F)	48	Crie du Chat Syndrome	Shares with Clive and Richard	Since late teenage years
Marie (F)	60	Bi-Polar General	Shares with 1 other female	Since late teenage years

		Learning Difficulty	not included in this research	
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*Names have been changed to protect identity

These four adults previously lived together with two to three others in a bungalow built in the 1990s. They moved there as part of a first phase of moves from a large Learning Disability Hospital. The Reprovision Project used Circles of Support to decide where each should live and with whom. Richard, Clive and Annabel demonstrated recognisable relationships and were permitted to continue living together. There was some concern that the three people's individual needs would not be identified and supported as well living together than if they lived apart. Their Circle agreed, however, that separating them was potentially more detrimental than them continuing to share. All were allocated 12 hours of individual day time support with night support being shared. A dormer bungalow was bought and adapted specifically to their needs.

Marie went to live in a refurbished bungalow with a woman of a similar age who previously lived next door to her. Like the other three participants, neither had capacity in relation to the decision, yet their known preferences were closely considered by their Circles of Support. Both women's families preferred their relative not to live alone due to safety and isolation issues. Following compatibility meetings, their Circles agreed the two women's similar needs, dispositions and

reactions to one another meant they could live comfortably together without the needs of one impacting deleteriously on the other.

Participant Observation

I chose an observational technique (Adler and Adler, 1994; Angrosino, 1998) for this study as they best answer 'What' questions (Blaikie, 1993).

Observations are strong in their ability to describe behaviours in context by looking in from the outside. They identify recurring patterns of

behaviour that those on the inside may be unable to recognise. This

method is used often in naturalistic human enquiry including research

with people with learning difficulties (Barnes, 1992). Observation is

nevertheless not without its problems (Denzin and Lincoln, 1998). It is

time consuming and, as Barnes and Mercer suggest, the participant

observation method can "introduce the problem of *reactivity*" (2010:21).

This means the individual may change the way s/he acts because of the

observer's presence. Although this may be problematic in short term

observations or with certain participants it did not affect this current

research, as the people were accustomed to my visits. If they had

altered their behaviour for this study this would have told me something

important.

The position of the observer and his/her relationship with those observed

is essential to determine as this will support or refute the assumed

ontology of the research (Blaikie, 1993). I specifically take on an

observer as participant role, where I am primarily an observer but do

participate in some interactions. This is similar to my advocacy role where I interacted with the people, observed what they were doing and asked questions of them and others about what was happening in their lives. The main difference was that I visited them more frequently over a short period of time. Enabling the participants to understand the difference between my role as a researcher rather than as an advocate was nevertheless important. Every effort was made to enable this role and relationship difference to be understood by the participants.

Although levels of understanding around this were probably minimal, I propose that my altered position did little to affect the research process or outcome.

Observational methods are said to go hand in hand with interviewing (Fontana and Frey, 1998a). Interviews are widely used within qualitative research (Kvale, 1995; Silverman, 1997; Fontana and Frey, 1998b) and finding the right methods to support individuals in interviews is crucial if the findings are to be authentic, valued and reliable (Lewis, 2002).

Brewster (2004) suggests using Talking Mats (www.talkingmats.com) to support communication pictorially. This low technology system uses simple pictures that can be placed on a mat to ascertain a user's thoughts and feelings in a visual manner. Consequences of actions or alternative choices can also be discovered, and participants can alter the line of questioning (Brunning and Steel, 2006). I have used Talking Mats in my role as an advocate and found them useful in involving some

people in decision making and sharing feelings. This method was, however, unsuitable for the four participants due to their levels of impairment; inarticulateness and unresponsiveness, issues identified by Clarke, *et al.* (2005), were apparent. My observations were supported instead by semi-structured “institutional talk” (Silverman, 2001:171), or talk on a professional basis, with staff members with the person present and included where possible. Enquiries were guided by the research questions:

1. What has changed in these adults lives now they have been discharged into the community?

2. What impact has the Repronision Project had on the quality of these people’s lives? The QoL indicators were used as specific topics for questions.

I took notes at each session; the participants are used to me writing when I visit, and, as always, I read out what I wrote. This allowed for verification of my observations with individuals and relevant others. I then took the notes away for reflection and interpretation.

Addressing methodological dilemmas

Human enquiry cannot be supported by traditional natural science approaches due to the involvement of free will that cannot be pre-empted (Blaikie, 1993). This point is, however, refuted by others (Blaikie, 1993). Not relying on numerical or statistical information and analysis used in quantitative research, for example; RADAR 1999 in Mercer and

Barnes (2010), might be said to make research less objective and scientific. Followers of highly positivist research methods critique qualitative methods, arguing that interpreted findings are unreliable due to the more subjective manner in which data is gathered and analysed (Smith, 1998). Barnes (1992) suggests that quantitative methods may be unsuitable in disability research that aims to be emancipatory, due to the need to involve oneself in the social world of the participants. Both Barnes (1992) and Mercer (2002) importantly note that effective research is not so much the paradigm, but the aim and approach of the researcher.

For research to have rigour the methods employed must be valid and 'truthful', and reliable or consistent over time (Silverman, 1997). These criteria come from a positivist tradition, however, and may not be useful in qualitative research. A different way of supporting qualitative research rigour is offered by Lincoln and Guba (1985). They argue that the practice of reflecting on the dynamics and content of an observation is inherent to weighing up the evidence and reaching an interpretation. This is more useful than claiming spurious objectivity. Instead of validity they suggest **credibility**, which refers to how believable the research is from the perspective of the participant. They also offer **transferability**, which refers to how generalizable the results may be across situations. For reliability they offer **dependability**. This refers to the researcher's reflexivity in considering all angles and circumstances within the

research. Following an examination of the challenge of the assumed subject–object dualism Lincoln and Guba offer **confirmability** instead of objectivity, suggesting:

The inquirer and the ‘object’ of enquiry interact to influence one another; knower and known are inseparable (1985: 94).

The following subheadings set out how the dilemmas were addressed in this research.

Credibility

Due to my circumstances I was unable to meet with the participants as frequently as I would have liked. I was also constrained to visiting at similar times of day. Community visits were not possible as nobody went anywhere at a time and day that I could manage. Visits therefore amounted to just 3-4 per person lasting approximately 2 hours each.

This was nevertheless sufficient to provide credible insight into different aspects of the people’s lives from their perspectives. I also viewed their diaries that noted all community outings and included notes from the accompanying staff. My previous knowledge and experience of the participants allowed me to observe any significant changes in the people’s behaviour and/or appearance. Observation of behaviour or response should not be assumed to be made in relation to a causal antecedent that no longer existed; therefore, although I facilitated empowerment and involvement within the research the level of involvement of the participants was undoubtedly minimal. Interaction

with significant others in their lives was therefore necessary for gathering essential information about the life and circumstances of that person on which to base interpretations and QoL analyses. Where needed, a group consensus was used to interpret meanings of the smallest of gestures, expressions and movements. This consensus approach further increased the credibility of the interpretations.

Transferability

This research takes place in only two homes. Despite this, the methods used could be transferred across other people, as their changes were all selected using person-centred criteria. The findings relating to service provision may also be extrapolated across the lives of other people the specific provider supports, and also between different providers.

Dependability

The ability of an observation to be replicable and therefore reliable in its interpretation can only happen if a person is subject to the same or similar experience over time, and the relationship with the observer is deemed safe (Lincoln and Guba, 1985). All meetings with participants as part of this evaluation were new encounters yet I worked with the people both before and after the Reprovision Project and had a good idea of the types and meanings of their behaviour and communications.

Observations were noted and carefully reflected upon to allow for dependable findings.

Confirmability

This study is an evaluation, therefore the knowledge produced will inform stakeholders of what may have happened as a result of a specific intervention; in this case the Reprovision Project. I bring a longitudinal perspective to the research and have had working relationships with some of the staff from the hospital days. My findings will therefore be confirmed by the historical knowledge I have of the people and the mutual trust shared with staff.

Ethical considerations

People determined as being vulnerable, such as those with learning difficulties, are protected by ethical standards that must be adhered to when research with or on them is proposed. The British Sociological Association (BSA) provides guidance on doing ethical research, including consideration of the Data Protection Acts, which considers confidentiality, and the Human Rights Act. I made a request to the Local Authority with the duty of care for these individuals if any ethics committee application needed to be made. This was not required. A similar request was made to- and response received from- the direct support provider.

Obtaining consent from people who lack capacity is a challenge when working with people who have learning difficulties (Cameron and Murphy, 1996). Since the implementation of the Mental Capacity Act (2005) people unable to give consent and have no one to make the

decision in their best interest must have an independent representative appointed (Boxall and Ralph, 2010). Some of the people in this research fall into this category and a request for support if needed was made to- and accepted by- the local advocacy provider. For people with families or friends willing to make the best interest decision for them a letter to formally ask for permission was sent within an outline of the proposal (Appendix B).

Safeguarding

The safeguarding of vulnerable adults is something for which all people have a responsibility. Safeguarding relates to how people are being looked after and refers to their human rights to be supported to live their lives without abuse or neglect (DoH, Social Services and Public Safety, 2006). Even though I no longer work for the people in the official capacity of advocate, if I saw or became aware of anything that required further advocacy support or other intervention then I would have passed this on.

My research practice was not adversely challenged due to these ethical considerations. Some staff members questioned my motivation for undertaking the research and I reiterated the need for my research due to the newness of In Control, Individual and Personal Budgets. The concerns highlighted previously by Smith and Chambers (2011) and Pitt (2011) also suggests this research is required.

Method of analysis

Continuing with my qualitative approach, I used a thematic method of critical analysis (Denzin, 1998) that suited my research data. Thematic analysis has been described by many qualitative researchers in different social science disciplines (Rubin and Rubin, 1995; Kvale, 1995; Boyatzis, 1998; Ziebland and Chappell, 2004). I identified two main themes for analysis: 'Environmental changes' and 'Changes of service provision'. I considered the impact of the Reprovision Project on

Independent Living, establishing valued social roles and becoming a citizen using 9 indicators (Continuity, Choice and Influence, Status and Respect, Community presence, Partnerships and Relationships, Competence, Individuality, Wellbeing, Safety and Security) as specific QoL criteria. Individuals' age, gender and level of impairment were also considered.

In this chapter I have shown how I approached my study. I have set out how I collected my data, the dilemmas encountered, ethical considerations and my method of analysis. In the next chapter I begin to discuss my findings.

Chapter 4: Environmental Changes

A significant change in the lives of all the people within the Re provision Project is their living environment. Institutional care, the legacy of Victorian workhouses, remained the only option for many thousands of people with learning difficulties until the Blair Government reform (Emerson and Ramcharan, 2010). Even the campus homes built outside the wards remained fundamentally, and legally, hospital wards. They were organised and managed in the institutionalised manner of the NHS and the residents were patients.

In line with **Independent Living** the people who were part of the Re provision Project now have their own homes within ordinary communities in private, quiet residential areas. Marie now lives with just one other, whilst the other three continue to live together. This change theoretically supports opportunity for establishing **valued social roles** and **citizenship**. The following sections consider findings from the QoL indicators to see how the environmental changes appear to have impacted on the life quality the participants now have.

Continuity, Choice and Influence

When the four participants moved into their new environments in July 2010 they brought with them photos of the past and mementoes from former housemates to support continuity of their past into the present. Continuity of routines and rhythms to minimise the effect of other changes in the people's lives were also considered important prior to the

move; observations suggested that these were being continued and even developed within the new environment.

Despite 'choice' being paramount to the Re provision Project, the possibility of staying within some type of residential care was not an option for anyone. For the four participants in this research this was not an issue, yet for some of the Re provision Project's participants, alternative residential accommodation choices may have been preferable. The residents themselves, or even their Circles of Support, were not 'in control' of this aspect of the Re provision Project.

The previous homes offered little that supported choice-making in any meaningful way. Equipment to enable this was explored prior to the move in line with **establishing valued social roles** and **becoming a citizen**. Different switches for working lights, TV and music were considered and tried, yet none were suitable. Automatic door and window openers were also of little use to any of the four participants due to their levels of impairment. Staff must act on behalf of individuals in relation to their environmental needs, which highlights the need for staff to understand the preferences of the person.

Moving around within the home must also be supported by the staff for most of the participants. The designs allow easy access by wheelchairs and ceiling hoists have been provided where needed. Although these permit ease of movement the choice to move must be pre-empted by staff. For Annabel, however, who can move around independently to a

limited degree, the size and layout of the home facilitates her choosing to move where she wants to more easily. She will take herself to her room when she wants to go to bed, or she will move into another room if she wants to know what is happening in there.

Status and respect

The design of the previous home supported privacy and dignity in that each had their own bedroom yet six people had to share two bathrooms. Staff rightly supported individuals' to use the bathroom alone, therefore, there were times when a person could not access the bathroom when necessary, leading to an undignified wait. The new environments much better support the status and respect of the residents on at least two levels. First, each person's bedroom is larger, so they have more space for relaxing alone. All rooms are appropriately lit and decorated according to the known preferences of the individuals. Doors are closed to preserve dignity and peace when needed.

Second, the wait for bathrooms has ceased. Marie's home, shared with one other plus two staff, has two toilets and one bathroom. Marie is able to access what she needs when she needs it without having to wait in turn. Annabel, Clive and Richard live together with three staff during the day. There are three toilets and one bathroom. Only Richard uses the toilet regularly. Annabel and Clive are both doubly incontinent and are often changed in their rooms, where there is now sufficient space. They do however need to regularly access the bathroom. Staff said that

individual's preferred routines mean that no-one's dignity is compromised by the environment.

Community presence

A concern within the Re provision Project was that the people would be isolated in their homes. The environmental changes *per se* allow for better inclusion in the community as continuation of segregation often experienced within hospital homes (McClimens and Richardson, 2010) is removed. This supports opportunity for **establishing valid social roles and citizenship**.

Changes in living arrangements have coincided with changes in community environment opportunities (DoH, 2001). The local plans and processes to close day centres for people with learning difficulties (Northamptonshire County Council, 2010) coincided with the moves. Of the four participants, Richard is the only one to have previously accessed a day centre run by the Local Authority. As he now has his own budget he no longer uses day centre placement as an alternative place to go. He is said to visit the local library regularly and has pub lunches with his housemates. Although Clive, Annabel and Marie did not go to another institutional environment they still went out before the move, albeit irregularly. Annabel now visits the local swimming pool each week. She, Clive and Richard also visit large community events, together and separately, using their budgets and support plans.

Prior to the move Marie was a member of a local older people's 'Village' complex. Here she enjoyed flower arranging and musical sessions.

There was active exploration into whether Marie should live permanently at the Village but unfortunately there was no apartment available.

Although she still attends she is visiting less frequently than before the move, as she is going out at least once practically every day to do other things. Her 'Community Involvement' book was filled with evidence of daily visits to shops, walks in the park, lunch out, the local library, Church and other places.

There was little evidence of the outside community coming into the homes as yet (Seebohm, 1968; Nunkoosing and John, 1997). A masseur continues to provide home treatments but neighbours do not appear to be actively welcomed. This issue is taken up in the following section.

Partnerships and relationships

O'Brien and Lyle O'Brien (1991) listed forming relationships as a key accomplishment for people with learning difficulties to achieve community integration. Nunkoosing and John (1997) and Hogg (1998) noted how difficult this could be if opportunities were not supported to enable relationships to be formed. The new environments are better for receiving visitors than the previous homes, despite the smaller size. The feel of the homes is not institutional, as there is no office or industrial washing machine. The home itself is an ordinary bungalow in an

ordinary street amongst other ordinary homes. Inviting the community in would facilitate inclusion and assist in developing valued social roles and citizenship (Mansell, 2005). This is explored further in Chapter Five.

Competence

Competence of disabled people is fundamentally related to support (Crewe and Zola, 1987). The home design aimed to support people to be competent within their homes in the same way or better than previously (see 'Choice and influence' section in this chapter). Communication was a specific competence identified for this research yet the changed environment does not impact on this. It is considered further in Chapter Five. The following observations around other competences were noted:

Annabel moves around on her knees although she does have arthritis in her hips. Now the environment is smaller she is able to reach where she wants to go more quickly. She now spends far longer on the floor engaging with balls and socks, which she loves to throw about, and engaging with her surroundings

No change was observed in Clive's competences in the new home. He always used to roll on the floor when he wanted to and continues to do this. He also continues to examine and happily shake his maracas and other noisy stimulatory equipment he is given. He can access the dining table easily and can use this for activities when appropriately supported.

Richard continues to rock in his chair and is usually compliant with moving around in his wheelchair. He was however competent at getting on the floor in his previous home, but has not done so since moving. Richard's visual impairment may mean he is not confident at moving out of his chair alone in an unfamiliar environment. The smaller floor space directly in front of his chair however may also contribute to this change, which service providers should address.

On the other hand, Marie's sociability is positively affected by the environment being smaller. She no longer has the choice of sitting with four or five noisy others, or on her own in a separate room for long periods.

The four participants did not appear to benefit from the changed environments to be included in ordinary tasks, such as cooking, laundry and other chores. Despite their impairments the four could still be included in household chores, albeit passively. Individuals' choice not to take part could be the reason; however, this may be a service provision issue, as competences in these areas have developed for others within the Re provision Project.

Individuality

Individuality is key to Valuing People (2001) and In Control (Duffy 2003). The three reports by Poll, *et al.* (2006), Hatton, *et al.* (2008) and Tyson, *et al.* (2010) refer constantly to people's individuality. This

indicator was always identified and supported as much as possible in the Healthcare Trust homes and has increased as a result of the move.

Everyone has a comprehensive person-centred plan and the environments positively support individuality identified within those plans. For example, none of the participants went to live with anyone that was unsuitable for them. Noise levels in an environment's surroundings and its proximity to shops/ countryside/ amenities were also all considered from an individual perspective. The individuals' histories and family backgrounds were thoroughly explored to ensure as much information as possible had been identified to facilitate the choice of environment lived in, and listed as places to visit for leisure. All alterations and adaptations were carried out to suit the individual(s) living in each home and extended to the gardens.

The following observations were noted:

Annabel moves on her knees and needs a soft surface to move easily. Brightly coloured soft mats that clip together were bought to cover the concrete patio so that she could happily go outside.

Richard appears to enjoy the sound of birdsong so his new home with established trees is appropriate for him.

Marie enjoys her garden so an accessible, easy to maintain area is essential to her. Raised beds and pots were purchased to enhance her participation in the garden.

Wheelchair access is necessary for Clive, Annabel and Richard and this was established prior to moving in.

Wellbeing

The points highlighted by Kerr, *et al.* (2003) and Michaels (2008) can all be seen to have been considered and applied to the Reprovision Project. The change in environment has not impacted upon primary healthcare for the four participants, as all have remained with the same GP who has a particular interest in people with learning difficulties. My observations suggest that the change in environment has however impacted positively on the general wellbeing of the participants. Both Annabel and Marie are more active in their daily lives and exhibit fewer anxieties. Annabel rarely sleeps on the settee during the day and accepts food and drink much better than she has done for years. There was a time when her refusal of drink and food became a concern, as she could show signs of dehydration. Reflection and consideration amongst staff have concluded that the sunnier aspect of her new home has created this positive affect. The two men show less observable change in general wellbeing but do not exhibit any deterioration as a result of their new environment. The participants' spiritual well-being is being supported by a local church now that the Trust chapel has closed. This supports their **valued social roles** as members of a congregation, and status as **citizens**.

Safety and security

Due to the levels of support needed the four participants are considered to be very vulnerable. Living within campus accommodation was considered very safe by family members due to the location of the buildings and the perceived quality and quantity of support provided by medical personnel. Some people, however, were excluded from kitchens and bathrooms due to design, as well as approaches to risk management. A very clear agreement was made that no one should be excluded from any room in their new house because of a potentially harmful risk. Great care was taken to have lockable storage for hazardous chemicals and medications and to ensure kitchens were equipped for safe usage by the residents. My observations suggest this aim was being achieved. Furthermore, contact was made with community policing to support safety and inclusion within different neighbourhoods.

Summary

This chapter has discussed the environmental changes and how they have impacted upon the participants. The evidence gathered suggests that on the whole the changes in the environment have been positive and have facilitated an increase in the quality of the people's lives. This supports Mansell, (2005) and Clement and Rigby (2010). Further to Walmsley (2001), this has happened by establishing 'normality' as a "yardstick" when considering environments yet simultaneously

incorporating individuality. **Independent living** in 'normal' environments can increase the potential of the people to attain more **socially valuable roles** (Wolfensberger and Tullman, 1989) and begin to be seen as **citizens** within the community. Although the new environments support this, the realisation must be facilitated by staff (Nunkoosing and John, 1997; Hogg, 1998). The following chapter considers the second significant change in the people's lives; that of service provider.

Chapter Five: Changes to Service Provision

Prior to the Reprovision Project, the hospital residents lives had been controlled by professionals and the routines and regulations of a medical institution (Campbell, 2004; Hatton, *et al.*, 2008; Davis, 1990). Daily care was provided by Learning Disability Nurses and Healthcare Assistants overseen by Consultant Psychiatrists. Although service provision had become less formal in appearance over the years, with staff wearing ordinary clothes rather than uniforms, the philosophy of care delivered remained medically orientated. This chapter uses the selected QoL indicators to explore the data on service provision to determine how this change supports life quality.

Continuity

When the hospital opened in 1972 families had been promised continuity of care for life for their relatives within the hospital environment. The plan to change the service provider to the social support sector was initially met with fear and trepidation by staff and families whose thinking was entrenched in the medical model of understanding disability (Oliver, 1990a). Since the people were discharged continuity of care has been lost for a great number of people, particularly for those who have moved away from the hospital area. For the four participants, some continuity has been maintained as they stayed local with some established staff members transferring to the new service provider. This continuity may have facilitated a smoother transition to the new environments.

A selection criterion for participation in this research was that individuals should have moved into their new home for as long a time as possible. This was to potentially allow new staff teams to become established with routines and expectations. For various reasons this did not happen as anticipated. New staff did not get the time before discharge to work alongside the Trust staff to learn about the people and their individualities. Furthermore, the promise of each person being actively involved in selecting new staff members did not happen as expected, which was a denial of their rights (Rioux, 2002). Apart from the staff remaining from the hospital days the turnover also appears to have been higher than anticipated (Clement and Rigby, 2010). This suggests continued disruption of care and support development. Such occurrences do not facilitate **establishing valued social roles**. Fortunately the individuals' Person Centred Plans are well detailed to guide new staff.

Choice and influence

Theoretically the changes in service provision should mean the adults involved have more opportunity and support to make their own choices and take control of their lives (Crewe and Zola, 1987). Each person has been allocated money to provide individual support throughout the day time so each person can do what they want when they want, as **citizens living independently**. In practise, however, staff shortages have meant people have at times had to share a support worker for a time:

On one of my visits I found a former house mate from the campus was at Richard, Clive and Annabel's home. I was informed the person was at the home due to staff shortage. No choices were involved and all four people had to stay at home.

My enquiries fortunately suggested that this did not happen often, nevertheless it should never happen; each person has been provided with sufficient resources to facilitate individual support and choice making. Furthermore, the providers promised to over-staff teams to provide a staff bank. This issue was not evident within any of the three In Control reports.

Before the move, active choice-making was often assumed by staff to be akin to showing a person two options and then deciding for them which they should have. Following Collins (1996) and Valuing People (DoH, 2001, 2009) Circles of Support had identified appropriate methods to support real choice making where possible. Some evidence of this was observed as objects of reference were being used and more time was taken before assuming a decision. This shows that despite staff shortages the opportunity for individual choices to be developed has happened to some extent. This is particularly in relation to food and activities. For Richard, Clive and Annabel their choices may be reduced slightly due to them sharing a home, as one meal type is still usually cooked for them all. When I observed mealtimes, however, none of the

residents were ever forced to eat anything they clearly did not like or want.

One issue of concern observed was choice around the TV. In Clive, Annabel and Richard's home the TV was constantly on, as it had often been in the old home. When I visited it was not being watched and was still rather loud. Richard and Clive are known to enjoy music and when I asked I was told they go to their rooms to listen to music- or story- CDs. In Marie's home the TV was not on unless there was a programme on that staff knew she would enjoy. She was said to listen to the radio or music in her room if her housemate wanted the TV on. Choices were still being made for her but appeared more discerning than for the other three.

Status and respect

The philosophy of care underpinning the new type of support had the chance of changing the power dynamic that had traditionally undermined the status and respect given to the individuals (Taylor, *et al.*, 2007).

Evidence of poor dignity and respect was fortunately rarely apparent within the hospital service; regular visits by advocates helped highlight anything that could become problematic. Regular planned and unplanned independent advocacy visits to the homes are unfortunately no longer provided. In light of Winterbourne (Pitt, 2011) this may be seen as a great loss to the residents, as challenges to life quality could potentially go unchecked. Changes in service provision currently appear

to have had minimal adverse impact on status and respect; I observed a great deal of respect being extended to all four individuals in the way they were dressed, spoken to, supported and assisted by all staff members.

Community presence

The impact of the loss of the traditional day centre has been mainly positive on the people as ordinary places, not just those segregated for people with learning difficulties, become options (Finkelstein, 1980; DoH, 2001; Barnes, 2003; DoH, 2009). Richard's use of the day centre had been reduced over the preceding year from five to two days per week to acclimatise him to the change. The impact of any loss may have been worse if his routine of going to a certain place at a certain time had been stopped abruptly.

All four participants' support plans are clear about what they appeared to enjoy doing and actions have been taken to ensure their presence within the community reflects these. Marie appears to be getting out more than the other three and has established routines that have included her more in ordinary community life. She is supported to attend a local community Church regularly and stays for coffee after the service; this is an inclusive and **valued social role**. Losing the Trust Chaplaincy service had no negative impact on her. Support for the other three participants to attend Church has been less regular. I was told that staffing levels affected this. Plans for Clive to become more involved in community

activities with the local Boys' Brigade have also not come to fruition. He and Richard occasionally attend an art session in the community but this is only for people with learning difficulties, not an open session. Although some local inclusion projects have been established in the county, little exists that is suitable for many of the people with more profound impairments (Emerson and Ramcharan, 2010). This continues to highlight barriers for people with learning difficulties in accessing social opportunities (Zarb, 2004).

Community access with the new service provider has been affected by other issues. Clive and Annabel now have their own wheelchair-accessible vehicles and should be able to go out wherever they want to instead of having to wait their turn, as they did when living in NHS care. The problem is that some of their support team are unable to drive. They therefore either cannot go out or have to pay for expensive taxis; effectively paying twice for a journey. Neither Marie nor Richard has acquired their own vehicles. Marie is ambulant and has a bus pass as she enjoys using public transport. If she wants to go further afield she will pay her support worker mileage costs, as she is able to use an ordinary car. Marie has a Blue Badge to enable easy parking. Although Richard needs a wheelchair for mobility he can also access an ordinary car. However his support worker, who is a car driver, appeared unaware that Richard could pay mileage. On investigation it transpired that a Blue Badge had not yet been applied for Richard either. These issues should

have been settled prior to or very soon after the move and again highlight the needs for support providers to know the needs and rights of the people they work with.

Partnerships and relationships

Before discharge, the individuals' family relationships were actively encouraged and supported by staff. Marie's and Annabel's relatives visited the old bungalow often and were welcomed to be involved with their relative's care and wellbeing and to take them out. Relationships with family can be seen to have improved for Annabel since the Reprovision Project as her parents now visit at least twice per week and they interact well with the men as well as their daughter. Having her own vehicle has also meant that, if she has a driver, Annabel is able to visit her parents' home where her Dad has made a ramp to allow easy access.

Clive sadly has no family members who appear to want a relationship with him. Staff have tried to contact his brother to invite him to the new home but to no avail. Richard also has no family relationships. The only relationships that can be maintained for both men are those they have with previous staff members. The longevity of many of the Trust staff's careers meant that lasting relationships with the individuals had been forged. It often seemed that many staff spent more time with the people than they did with their own families; some longstanding relationships

are being maintained and relationships are being made with new workers.

Relationships with peers from life in the large hospital environment were previously maintained by staff organising gatherings in the homes. This is continuing in their new environments although the homes are smaller; Annabel had a birthday party the day before one of my visits and there was plenty of party evidence; banners, balloons, cards and chocolate cake. The new providers do try to enable the four people in this research to meet up with former housemates on a reasonably regular basis; however, I was told that other people's providers may not facilitate this. Issues around transport, as discussed in the 'community presence' section, are also apparent.

Opportunities for meeting people and forming new relationships and partnerships have increased as a result of more community involvement (Hogg, 1998). Only Marie, however, is currently making any new relationships through her Church. All four participants regularly visit local pubs, restaurants, and the cinema, yet they seem to remain isolated within these environments as their staff appear to make little effort at integrating them by engaging with other patrons. Just because the people have the right and opportunity to be included in society, active engagement with others remains challenging to facilitate (Nunkoosing and John, 1997). This poor support may be due to confidence, training, or assumptions of social norms and expectations. This is also apparent

as I asked at both homes about the immediate neighbours. I was told that both homes' neighbours brought in excess vegetables from their garden plots. Marie's neighbours were also said to have swept the drive of snow during the winter. I asked staff if the neighbours were invited in for tea or for support such as cutting the grass; staff said they found both difficult to ask and did not want to impose. Engaging with neighbours and asking for this help could establish a relationship with new people. Relationships need to be facilitated by support staff (Nunkoosing and John, 1997) and staff reticence should be addressed by the provider management.

Residents were not supported or encouraged to form any private physical relationships in their previous environments (Evans and Rodgers, 2000). This presented an issue for few people within the Reprovision Project as a whole and not for any of this study's participants. For these people there was never any indication of a need to actively support a person's sexuality in anyway. This need was always explored at yearly life plan meetings but never appeared to need addressing. More intimate relations could potentially develop for some now they are no longer hospital patients.

Competence

In some respects the change in service provision has had little impact on the people's competences. In relation to communication Richard has a laptop bought before the move. It was bought with the plan that it would

be used to support his communication and appropriate software was to be loaded. I found that he rarely uses the laptop as his new staff members do not know how it works. Some are trying to 'have a go' with him without the instruction or support themselves to know what to do. As previously noted, the individuals need support to develop competences. This cannot happen if staff training is not in place.

Individuality

An issue brought to my attention at a presentation of my initial evaluation (Topp, 2011) was that some individuals were being over stimulated by their staff and had exhibited behaviours of stress and anxiety not previously seen. Although this was not evident in the four people I worked with, it is nevertheless a concern that must also be investigated and addressed by the providers. Activity plans must be regularly evaluated to ensure they reflect a person's individuality; adequate time must be available for relaxation as well as activity. The 'normalisation' principle (Nirje, 1980; Wolfensberger and Tullman, 1989) is evident here with Walmsley's (2001) warning again highlighted: 'normality' should be used as a measure of ordinariness.

The impact on individuality has been more apparent for some of the research participants than others. Marie has always been supported according to her individual needs as much as possible, yet the constraints of the NHS meant she could not always be supported quite as she would prefer. Her new support provision means she is now able

to develop her individuality. Annabel also has benefited from the increased level of support and opportunity afforded her as an individual when it has been available.

One of my visits to Richard followed a 'Best Interest' meeting for him. Staff had identified that he tended to do what others wanted, not what he might prefer. He was not being given opportunity to be an individual in the same way as were Clive and Annabel. This issue had been highlighted as a potential challenge when the decision had been taken for the three people to live together. The outcome of this meeting was to ensure Richard was taken to places and interacted with more individually. As the service provider had been unable to consistently place sufficient staff in the home the care and support had returned to a more institutional level that impacted more adversely on Richard. Questioning of staff revealed that Circles of Support established during the Project had deteriorated for many individuals. Circles are important to ensuring individuality is facilitated (Duffy, 2003). For those without family or staff who know them a wealth of knowledge will be lost about people that cannot speak for themselves. It is the responsibility of the service provider to ensure that Circles are maintained.

Wellbeing

A great concern at the outset of the Reprovision Project related to the new providers' ability to support the people's wellbeing, particularly in relation to health needs. Awareness of the need for stringent health

monitoring (Michaels, 2008) was high, as were the reports by Mencap (2007) and Abraham (2009). Living in a medical institution for so long caused family members and others to perceive that the people's general wellbeing was better supported by medical staff. In reality, the majority of the people had few medical needs and these were already being supported by a local GP. In some ways, living as patients within the Learning Disability Service may be said to have had an adverse impact in the people's general wellbeing; the restrictions imposed on nursing staff meant that certain procedures could only be performed by staff of certain grades. This had the effect of people potentially requiring emergency medication for epilepsy not being permitted to go out, as there was no suitably qualified staff member available. All new staff members are taught how to administer particular medications appropriately as required. Wellbeing is thus enhanced as activities can be undertaken despite a potential, yet rarely required, medical need. Additionally, everyone has a booklet containing details of his or her medical needs and signs to look out for. Each person also has a yearly consultation with their GP to ensure all checks are in place. The local Learning Disability Partnership Board continues to monitor the health provision provided by the Community Teams for People with learning Disabilities, and Strategic Healthcare Facilitators are available to support GPs.

Both Marie's and Annabel's general wellbeing can be seen to have particularly improved through the change in service provision. Marie has lost nearly a stone in weight and is less anxious as she is now given so much more interaction. No longer does she spend hours sitting on her own as she is sufficiently engaged in household activities, going for walks and shopping. Annabel's behaviour has significantly calmed as a result of the increased interaction she is experiencing. Clive has always had a cheerful disposition and this is being maintained by his new support provider's input. Only Richard's wellbeing is of some concern but there is a plan for its resolution, as seen in the *individuality* section.

Safety and security

Much work went into ensuring that every measure was being taken by the new providers to assure each person's safety. Area Team Managers were appointed to visit unexpectedly and this assists with allaying concerns. All new staff members have enhanced checks with the Criminal Records Bureau and all references are followed up. A negative impact on this indicator is suggested, however, with the loss of the dedicated advocacy service that previously supported all the people in the Project. Following discharge advocacy may only be referred to for issue-based work. This system relies on another person making the referral to the advocacy service, or if necessary to the safeguarding team. It is also a loss of an independent visitor who knows how to speak out for those unable to do so about everyday issues. The recent reports

about Winterborne (Pitt, 2011) raise questions about the need for adequate advocacy provision for people with learning difficulties.

Summary

This chapter has explored evidence in relation to the people's quality of life due to the change of service provider. The evidence found here suggests that, for Marie and Annabel at least, their quality of life has been enhanced by the change in service provision. There are negatives, however, particularly in relation to *relationships* and *community* opportunities. There are also some losses, and even after nearly a year some individual's plans have yet to be fully met or support appropriately managed. This is highly significant for the participants and must be promptly addressed.

Chapter Six: Conclusion

This evaluation research explored the lives of four people who had recently been discharged from hospital care and accommodation into ordinary community living. Two questions were asked:

1. What has changed in these adults lives now they have been discharged into the community?

2. What impact has the Reprovision Project had on the quality of these people's lives?

To answer these I used a qualitative social model of disability approach to undertake participant observation supported by informal 'institutional' (Silverman, 2001) interviewing with staff. In this research the number and circumstances of the participants were very limited; therefore, the breadth of findings is undoubtedly restricted. Lincoln and Guba's (1985) alternative criteria of credibility, transferability, dependability and confirmability were nevertheless used to address challenges of research rigour. The qualitative analysis method met the aims of the research and the needs of the participants. The research methods used here could be adapted if a larger study were to be undertaken. The answers I have drawn out are not the only 'truth' that may be found, however, as alternative methods and other participants could provide differences.

Findings

Two fundamental changes were identified in the people's lives; 'environment' and 'service provision'. The Reprovision Project impacted

on the participants' life quality by providing opportunity for **Independent living, establishing valued social roles and becoming citizens.**

These are posited as general requirements for people with learning difficulties to have a quality life (see Chapter Two). To consider more individual experiences eight specific QoL indicators from the Watching Brief (Sterling, 2007) were used: **Continuity, choice and influence, status and respect, community presence, partnerships and relationships, competence, individuality, and wellbeing. Safety and security** (Hatton, et al., 2008; Tyson, et al., 2010) were also applied. All of these domains varied in how positively any impact affected the participants.

Further to Topp (2011), the data gathered for this research suggest that since the four participants were permitted to **live independently** their quality of life has changed, yet not all outcomes have been as positive as predicted. Improved living environments allow for more individualised and dignified lifestyles, yet there are significant differences in the quality of life lived in the two homes. These differences are not so much about the environment, as the support provided; which is reflected in Clement and Rigby (2010). A concern at the Project's outset was that living alone or with just one other may have brought with it loneliness and isolation; evidence in this research does not support this, suggesting instead that the opposite is apparent.

Establishing **valued social roles** is also about support and appears most evident for Marie, as she is supported to engage more with her Church community. Generally, however, social roles remained minimal for the participants as they did not appear to be well supported to engage with others (Nunkoosing and John, 1997).

Citizenship is defined by Rioux as “a dynamic relationship along three complementary dimensions: rights and responsibilities, access, and belonging” (2002:216). In Control (Duffy, 2003), used by the Reprovision Project, aims to provide citizenship for all. Evidence in this research suggests that this aim is being worked towards, but is not yet fully achieved. The participants have the resources to maintain their rights and responsibilities to live as ordinary members of the community, not as ‘stigmatized’ (Goffman, 1963) patients. Nevertheless, ‘access’ remains impeded when staff cannot drive, and suitable opportunities for inclusive leisure do not exist. ‘Belonging’ is not supported when staff cannot engage with people in the community on behalf of the people they support.

Community presence, particularly in the home, **partnerships and relationships**, and some **competences** appear to be less positively supported and developed than the other domains. Delays in establishing staff teams with appropriate skills meant new opportunities for involvement within these domains were not yet actively being implemented and developed for some.

Further recommendations

These findings suggest that further independent research is called for to evaluate the lives of all the people within the Project following discharge. Further research could use this small study as a step to undertaking a much broader project that includes all people discharged and perhaps also makes comparisons with similar projects across the country that did, and did not, use In Control as a foundation.

Summary

The move from NHS campuses has been a positive step in many ways. Leaving an institution undeniably supports the social model, and provides better opportunities for social inclusion and individuality. As this research shows, if support is to provide the highest quality of life, then it must be personalised (Emerson and Ramcharan, 2010). Improvement in the people's lives will only continue if the service providers remain vigilant in developing such a service (Mansell, 2005; Clement and Rigby, 2010). The re-establishment of a dedicated advocacy service for people with learning difficulties would also help ensure services remain personalised.

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Appendix A ***Letter Sent to Prospective Participants***



Hello name
My name is Jackie.
I used to visit you as your advocate.
I want to visit you again. This time I
will be a researcher. This means I
want to find things out.



I want to find out how life is for you
now you have moved.
I want to see if you are happy.

I want to know what you are doing.

I want to know if there is anything
you don't like about your new life.



I have written to your circle of support to tell them more about what I want to do.



You do not have to see me if you don't want to.
Your circle will help you choose.



Best Wishes, Jackie Topp

Appendix B *Research Proposal Sent to Circles of Support:*

Evaluating the Quality of Life of People with Learning Difficulties who were Discharged from Hospital Care and Accommodation

Following my work last year that evaluated the Reprovision Project I would now like to work with a few people from that project to see how their quality of life has changed since being discharged from hospital care and accommodation.

This letter is say that I would like to consider name to be one of my participants.

I intend to work with name quite closely over a period of about 1 week during May 2011. During that time I will visit name at her home and will also meet her at places in the community where she regularly or occasionally visits. I will be meeting name at different times in the day and will be observing what she is doing as well as joining in with what she is doing where appropriate.

During my visits I will make notes about what I observe and what is told to me by staff and other people at the time. Importantly I will be using different methods to try to enable name to let me know how she feels about what she is doing and also the ways she now lives her life. To be clear I will not be doing any personal care or providing any other service during my visit.

As name is considered to be a vulnerable adult who is unable to give consent to taking part in a research project I would like to ask you along with other members of her circle of support if you have any objection to me working with her.

Due to my limited resources I am unable to work with many people and have to identify just 3-4 individuals to work with. Nevertheless I hope my findings will be used by name's support provider and Northamptonshire County Council to identify anything missing from a person's life, and to continue to improve the quality of life for name and all the people with learning difficulties who were part of the reprovision project. Please be assured that my reason for doing this project is in the best interest of the people taking part and potentially for those with whom I could not work.

My findings will be available from September 2011.

If you have any further questions about my project please do not hesitate to contact me on 07517 052272, or my supervisor whose details are in the box below.

Many thanks
Jackie Topp
MA Disability Studies student

Dr Laura Hemingway Dissertation
supervisor
Leeds University
L.J.Hemingway@leeds.ac.uk

Appendix C

Letter of Thanks Sent to Participants

July 18 2011

9 Holman Close
Northampton
NN3 2TF

Jmc7@btinternet.com
07517 052272

Dear names

I write to thank you for letting me come to speak with you recently. It was lovely to see you again and I must say how well you all looked. I am pleased that the Reprovision Project seems to have worked for you.



When I visited I found out lots of information about what you are doing in your new lives. I was able to write about this for my MA dissertation. I will share my findings with all interested people after September. I hope my work will help mean the services you get are what you want, both now and in the future.

Thanks again
With very best wishes

Jackie Topp

