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'An investigation into why some people with learning difficulties who have part time supported employment in mainstream settings continue to use segregated employment training facilities'.

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Abstract

This project explores and examines significant elements in the part time employment and daytime activity relationship of people with learning difficulties by looking at the reasons why some people continue to use segregated employment training facilities even when they have gained part time employment in mainstream settings.

Although a small-scale project, it firstly explores a wide range of evidence on day services, employment services and sheltered work environments including recent policy developments, secondary statistics and relevant documents. It adopts an approach committed to the social model of disability, with disablement perceived as resulting from social exclusion rather than individual bodily functioning.

It considers whether the way some of these services have developed and persisted may have contributed to the continuation of the exclusion of people with learning difficulties from aspects of mainstream life. It also examines how the limited options that have been available to people with learning difficulties could have contributed to their continued use of segregated services.

Secondly, it presents a snapshot of the current picture by means of a small-scale piece of fieldwork by contrasting the alternative perspectives of people with learning difficulties who have part time employment, their parents, carers and employment staff through qualitative face-to-face interviews.

Chapter 1: Introduction

Background

The focus of this research is an exploration of why people with learning difficulties (PWLD) continue to use segregated employment training facilities when they have successfully accessed part time supported employment in mainstream settings. In particular it examines the reasons for this on an island with a population of approximately 60,000 people, which is one of the Crown Dependencies. Please see Appendix 1 for background information on the research setting.

As a non-disabled person, I have worked as a staff member in a variety of roles and in various establishments *for* disabled people for over thirty years, both in the UK and in this island community. My interest in this particular topic stems from my experiences in Day and Employment Services for PWLD.

The observations I have made raise questions about the continued use of segregated day time work-related facilities and particularly their continued use by PWLD, who have been supported to gain, and are successfully working in, part time employment.

In 1971, the White Paper, *'Better Services for the Mentally Handicapped'* (Department of Health and Social Security, (DHSS) 1971), was produced and laid the foundations for 'Care in the Community', which supported individuals with a learning difficulty to live 'as normal a life as possible' and be 'integrated' into society. Although much progress was made in getting people out of large

institutional hospital settings, many separate specialist services took hold and although they may have been *in* the community, many were not, and are still not, part *of* the community. Adults with a learning difficulty may still find themselves amongst the most marginalised people in the community (Simons, 2000; Hall, 2004), some thirty seven years later.

Working-age PWLD are significantly less likely to be employed than people without disabilities, (Department of Health, (DOH) 2001) and although many would like to work (Kilsby & Beyer, 1996; McConkey & Mezza 2001), a large proportion have limited options and are likely to use segregated day services.

For decades, services for PWLD have been dominated by large, often institutional, day centres under such names as adult training centres, social education centres and day centres providing wide variations of what people actually do in them (Simons & Watson, 1999). Previous research has suggested that disabled people use day services because there is 'nowhere else to go' (Carter, 1981; Barnes, 1990) and resources have been put into congregate settings. When the King's Fund (1994) undertook a national consultation exercise on trends in services for PWLD in 1993, they found that the majority still spent most of their waking hours in congregate, segregated settings with their lifestyles largely dictated by the limited choices that were offered by those services (Whittaker & McIntosh 2000, p.3).

The White Paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (DOH, 2001) was published in the

UK in 2001, some thirty years after the publication of the White Paper, *Better Services for the Mentally Handicapped* (DHSS, 1971). It set the agenda for achieving the goal of what Tony Blair stated as 'a modern society in which everyone is valued and has the chance to play their full part' and set out the UK Government's commitment to improving the life chances of PWLD. At the heart of the proposals are the four key principles of: Legal and Civil Rights, Independence, Choice and Inclusion to enable PWLD to have as much choice and control as possible over their lives and the services and support they receive (DOH, 2001, p.10), but is this a reality for many PWLD in 2007?

Day services are in the process of being 'modernised' (DOH, 2001; Cole *et al*, 2007) but service users, staff, parents and carers are often entrenched in the acceptance of these separate, specialist institutions fashioned to meet the needs of people grouped together and 'warehoused' under 'medical model' provision and reasoning.

When PWLD do get part time employment, they are likely to still spend time in segregated settings, unlike their non-disabled peers who have part time employment. This is largely because revenue is tied up in large inflexible services (Cole *et al*, 2000). Rather than receiving the support they need to participate in ordinary community activities outside of segregated services, they may have difficulties in getting the required support needed for more individualised lifestyles, with the choices and control that they would like.

Aims and objectives

This dissertation raises the question:

‘Does the way that day and employment services are organised contribute to the continued use of segregated employment training facilities when PWLD have part time employment in mainstream settings?’

The research has two aims. The first is to explore the reasons why some PWLD continue to use segregated work related day service facilities when they are successfully employed in part time supported employment in mainstream settings. The second is to produce and disseminate the findings, after the research has been completed, in a variety of accessible formats, to PWLD, parents, carers, professionals and senior managers within the local Health and Social Services Department to initiate further debate.

The key objectives of the research are to:

- Review the existing literature on the continued use of segregated day and employment services for people with a learning difficulty.
- Explore what influences effect the decision to continue to use or not use the workshop base.
- Explore what people see as possible alternatives to remaining at the workshop base.
- Examine how or what information is gained about alternative possibilities to using segregated work related day service facilities when in part time employment.

- Highlight emerging issues and themes.
- Initiate further debate on these issues and themes among people with a learning difficulty, service providers and parents/carers.

Data collection

The main data for this research will be generated through contact with two different groups of PWLD; two groups of their parents or the support staff from where they live and the staff group from the employment service. This will cover different dimensions of, or perspectives on, the reasons why PWLD continue to use segregated work related day service facilities when they have successfully accessed part time supported employment in mainstream settings.

First, qualitative semi-structured individual interviews will be conducted with three PWLD that have part time work and continue to use segregated work related day service facilities and three people who have part time work and do not continue to use segregated work related day service facilities.

Second, qualitative semi-structured focus group interviews will be conducted with the two groups of parents or support staff of the people who either continue to use or do not continue to use segregated work related day service facilities when they have part time employment, which will involve exploring their ideas about this aspect of their lives.

Third, a qualitative semi-structured focus group interview will take place with the staff from the employment service workshop base to explore their views on the subject.

Outline of the project

The following chapters will examine the current literature and secondary data available; the processes of data generation used in this research, and highlight the findings.

Chapter two considers the social and medical models of disability and the influence of the principles of normalisation. It examines the current literature on day services, employment services and sheltered work environments and considers how the development of these may have contributed to the continued exclusion of PWLD from mainstream life. It will also examine the limited options that have been available to PWLD and how this could have contributed to their continued use of segregated services.

Chapter three examines the methodology underpinning the research; it will look at the involvement and participation of PWLD in research and various approaches to this. I will discuss my approach and outline my reasons for using qualitative research methods. This will be followed by a section on the planned data collection strategies to be used including a discussion on sample selection, the use of qualitative interviews through individual and focus groups and dissemination and will examine their strengths and weaknesses in relation to the study. Ethical issues will be

considered including consent, confidentiality, anonymity and privacy.

The next two chapters will present and analyse the findings of the study. Chapter four will examine the information obtained from the accounts of PWLD and include a discussion of the steps taken in the data analysis. Chapter five will examine the information obtained from the accounts of parents, carers and employment staff.

This will be followed by the conclusion in Chapter Six which is a discussion of the findings.

Chapter 2: Disability, learning difficulties, day centres and employment.

Introduction

The objective of this stage of the research was to review the existing literature on the continued use of segregated day and employment services for people with a learning difficulty and the reasons for this. It focused on whether the way that day and employment services were organised, contributed to the continued use of segregated facilities when PWLD have part time employment in mainstream settings and also considers the area of person centered planning in relation to this.

Throughout the developed world in most industrialised countries, paid work is a key signifier of class, social standing, worth, status and power (Barnes and Mercer, 2006, p.186) and is viewed as a means of access to friendship, community and valued occupation (Clark, 2001). Work is one of the major defining roles in our lives and provides structure to our week as well as generating income (McIntosh and Whittaker, 1998). Ordinary work remains the main form of daytime activity for the majority of adults and given a choice, many PWLD aspire to employment as a key life goal (Reid and Bray, 1998; Riddell *et al*, 1999a; Beyer *et al*, 2004). PWLD like and dislike work for much the same reasons as everybody else, as indicated in *The Working Lives* report, in which PWLD identified the advantages of paid work as money, social contact, making a contribution to other people and having something to do (Beyer *et al*, 2004, p.1).

Disabled people however, are amongst those on the margins of the labour market and experience a variety of economic, political and social deprivations by their exclusion and disadvantage in the labour market. These factors significantly undermine the rights of disabled adults to participate fully and equally in society (Jolly, 2000).

PWLD are amongst the most vulnerable and socially excluded in our society but they would like to participate fully and equally in society with rights, independence, choice and inclusion (D O H, 2001, p.14). Many would like to work in mainstream employment but do not have jobs and others who have employment are more likely to be employed on a part time basis (Beyer *et al*, 2004, p.1).

Disability and people with learning difficulties

In this research project, I will refer to people with 'learning difficulties', as opposed to 'learning disabilities', as self-advocacy organisations such as People First (1995-2004) have expressed a preference for that term, although 'learning disability' is used in many Government documents both in the UK and by the informants using services in the island.

This island has a register of people with a *learning disability*, the criteria for which is in Appendix 1. All the informants in the study meet the criteria to be on this register and registration is needed in order to access services.

From an ontological perspective, people with impairments have historically been discriminated against in all areas of their lives along with other people in society such as gay and lesbian people, women and people from ethnic communities.

The underpinning epistemology for this research will approach disability from a social model perspective where disability is viewed as a consequence of social, environmental and attitudinal barriers, rather than a consequence of individual bodily functioning, as in the medical or individual models of disability. The concept has its roots in the work of Hunt (1966) and The Union of Physically Impaired Against Segregation (UPIAS) along with the Disability Alliance, who in the 1970's played a pivotal role in the move away from an individual/medical model interpretation to a focus on the social dimension. This resulted in developing a clear distinction between the words "impairment" and "disability" which demonstrated that impairment is a biological condition and disability a situation brought about by social conditions leading to the oppression of people with impairments (UPIAS, 1976). Disability, within a social model approach, is a socio-political issue that concerns society as a whole and can be seen to be created by the failure of people, organisations and social systems to respond appropriately to the everyday support needs of people who have impairments (Carson & Speirs, 2004, p.48).

During the 1970s and 1980s a very different ideology was being developed in relation to PWLD. The concept of normalisation was the dominant force and unlike the 'mainstream' disability movement at this time, this 'movement' was dominated by non-

disabled people and focused on services and service evaluation, which has been criticised by some, as being professionally driven (Chappell, 2000; Walmsley, 2001). The idea is that PWLD *deserve* to have the same opportunities, to enjoy 'normal' patterns of life, as the rest of society (Nirje, 1980, p.33). Although normalisation influenced the delivery of care and helped to change the way services were planned and delivered for PWLD, it only sought to 'enhance' the lives of disabled people, without seriously addressing or attributing disability to the oppression and exclusion of the disabling society in which we live. The process of 'normalising' people and services was stated by Oliver as 'building, reinforcing and maintaining the 'normal/abnormal dichotomy'' (Oliver, 1994, p.12).

Research undertaken in the context of normalisation theory would profoundly influence the research process towards a focus on 'normalising' or changing individuals to reduce deviance and stigma rather than social change (Chappell *et al*, 2001). I will therefore adopt the social model of disability, with the aim of the research being to bring about social change and the emancipation of PWLD.

Day centres, employment services and sheltered work

When considering the existing information on the continued use of segregated day and employment services, the history of the development of these services needs to be examined.

The conventional idea of day 'care' for adults with learning difficulties was based on the concept of the 'centre'. Although day centres in one form or another have been in existence since 1913, traditional day centres were set up in most local authorities by the 1970's (Simmons & Watson, 1999; Beyer *et al*, 2004). These were originally conceived as 'occupation centres' with an emphasis on sheltered work. Some of the first day services in workshops and training centres, often took on contracts from local firms for work such as packing and light assembly. The people who used these centres were often labeled with the term 'trainee' and although they may have received some money, often referred to as 'attendance allowance'; they did not get paid proper wages and very few moved on into real jobs (Corporate Document Services, 2006).

Although the focus of these centres has shifted over the years and these have been called occupation centres, adult training centres, day centres and social education centres, their purpose has remained ambiguous. This institutional framework grouped people together and provided standardised services without regard to the variation of individual needs and interests. It could be argued that this in effect perpetuated segregation and led to the continued exclusion of PWLD from mainstream every day life.

As illustrated by O'Bryan *et al* (2000), traditional 'day services' became the automatic choice of PWLD when leaving school and as an institutional form the day centre has shown remarkable resistance (Simmons & Watson, 1999, p.15).

The lifestyles and day opportunities of many PWLD are still largely dictated by services where the planning process may focus on the allocation of resources, rather than looking at the support needs for the person to access an ordinary life and where they have routinely been expected to fit into existing services (O'Bryan *et al*, 2000).

Recent UK documents have highlighted that the concept of daytime support being provided within the congregate, institutional, segregated structure of the centre is now being challenged (Wertheimer, 1996; DOH 2001, Scottish Executive, 2006; DOH, 2007) and the 'modernisation of day services' is underway. The process and speed of implementing these changes however is varied (Cole *et al*, 2007).

In the *Valuing People* report in 2001, local councils were reported to be spending over £300 million a year on day services, of which more than 80% went on over 60,000 day centre places that often focused on large, group activities (DOH, 2001, p.77).

For PWLD, the White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* set a five year plan for improving their lives and those of their families and carers, based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent (DOH, 2001, p.17). It acknowledged that many PWLD do not live in their own homes or have choice over who cares or supports them and that very few had jobs, probably less than 10% (D O H, 2001, p.84). It set the objective of enabling PWLD to lead

full and purposeful lives in their communities and develop a range of activities including leisure interests, friendships and relationships.

In 2005, around 3,000 people contributed to a follow up report, *Valuing People: The Story So Far*. It identified that although there has been some good progress in some areas, where some people's lives have changed dramatically, for many people little has changed and delivery has been patchy across the country (DOH, 2005). Cole et al. (2007) identified that many local authorities are still struggling to move away from large congregate settings where development is affected by the local, social, political, economic and demographic circumstances and development has been a varied and evolving picture around the UK.

In 2007, the knowledge review: *Having a good day? A study of community-based day activities for people with learning disabilities* (Cole et al, 2007) was carried out for the Social Care Institute for Excellence (SCIE) by a team from the Foundation for People with Learning Disabilities (FPLD) and Norah Fry Research Centre (NFRC). It comprised a research review and a practice survey, which set out to identify what has, and what has not, contributed to successful provision of community based day activities for PWLD. 'Community-based day activities' were taken to include employment, adult learning and further education and leisure activities undertaken away from a person's home. This recent review identified that in the past 20 years there has been a

significant paradigm shift, from people having a 'day service' and going to a day centre, to services supporting people in:

- workplaces
- education classes and colleges
- sports and leisure centres
- local community centres
- and around local villages and towns. (Cole *et al*, 2007, p.1).

The study was all about what needs to happen to develop community-based day services so that people can have ordinary lifestyles and 'have a good day'. Having a good day was described as:

- doing things that have a purpose
- being in ordinary places, doing things that most members of the community would be doing
- doing things that are right for you
- receiving support that meets your needs
- being in touch with local people, meeting people and developing friendships. (Cole *et al*, 2007, p.2).

The knowledge review however also identified that in 2005 a national survey of PWLD (Emerson *et al*, 2005) found that 39% of all PWLD were attending a day centre and two-fifths of them were attending five days a week. The same survey also found that only one in six had a paid job, compared with two thirds of men and half of women in the general working age population. Two thirds of the people who were unemployed and able to work said that they wanted a job but the range of jobs available is narrow, with a pattern of low hours and low wages.

It is clear that too many PWLD still spend too much time in traditional day services (DOH, 2007, p.28). There is, however, a dearth of information on how many PWLD who are in part time employment use segregated day services as well as being in employment for part of their week.

Organisational and structural barriers have excluded many people with the label of learning difficulty from getting the appropriate support they need to meet their *individual* needs and interests (Cole *et al*, 2007). As stated by Dowson (1998), large day centres are not conducive to providing individual and person centered approaches and day services that are *only* buildings-based cannot be person-centred due to the way they are staffed, the rules, procedures and where the way the money has to be spent, means that running the service, becomes more important than what people want to do (Scottish Executive, 2006).

The priorities for the provision of services for PWLD over the years 2008–11 are set out in *Valuing People Now: From progress to transformation* which was published in December 2007. It now sees the term ‘day services modernisation’ as unhelpful as it still encourages people to think about buildings rather than needs and outcomes. Some have understood this as replacing large centres with smaller ones and as a result what people do with their time has hardly changed (DOH, 2007, p.29). It identified that the policy objective of supporting people to live the lives that they want as equal citizens in their community will require two important starting points, effective person-centred planning and forward planning (DOH, 2007, p.29). The outcomes from effective person-centered planning will inform planners what services and supports should be in place instead of traditional day services. It is highlighted that good person-centred planning can take time, however as evidence has shown that access to real paid work is most important to PWLD and it can open up other opportunities such as social

networks, it is hoped that effective managers will already be planning for this (DOH, 2007, p.30).

There are no specific requirements for day services themselves to deliver employment goals (DOH, 2001, p.11). The guidance document *Framework for Developing an Employment Strategy* (DOH, 2002) explores how links can be made between day centres and mainstream UK Government disability employment programmes. Day services vary in their understanding, approaches to, and involvement in, employment goals and have tended at best to do more work preparation, volunteering or work experience themselves and less job placement and support (Beyer *et al*, 2004, p.11).

The choices for PWLD who require supportive working environments are frequently limited to a few models of service provision including sheltered workshops, supported employment placements and social firms (Gosling & Cotterill, 2000).

Some local authorities developed sheltered workshops as an alternative to day services where contract work and a work ethos was promoted and an allowance was paid up to the maximum disregard allowance. The predominant assumption was however that if people worked at all, it would be mainly in sheltered settings and many were by definition seen as 'incapable' of work (Simons, 2000). Sheltered workshops have historically been the main employment related option for many disabled people, providing occupation and some earnings for significant numbers of people

but by their very nature of being 'sheltered' this has excluded them from being inclusive or progressive (O'Bryan *et al*, 2000).

An alternative view was developed when *An Ordinary Working Life* was published in the 1980's. There was a small but growing body of opinion that many people with a learning difficulty both wanted to work and could do so. It suggested that with the right support and adaptations anyone might be able to work and that people with a learning difficulty could learn more effectively on the job. The best way to help them into employment was to place then train, as opposed to the unsuccessful old training centre's approach which was supposedly 'train' then place, whereas stated previously the reality was that very few people moved on into employment as they were not deemed 'ready' (King's Fund Centre, 1984).

Supported employment developed originally to facilitate paid work for PWLD with ordinary employers in integrated settings where they would be welcomed and valued in their communities (Beyer *et al*, 1996). As alternative models of supported employment developed, with the central aim of supporting disabled people into employment, they were thought to be more effective and better value in progressing people into *paid* employment (Beyer *et al*, 1996).

The Association for Supported Employment defines supported employment as 'real work for real pay' which focuses on a 'place and train' approach and typically uses a combination of vocational profiling, job development, job analysis, flexible job support, career

support and places an emphasis on contacts and relationships with people without disabilities who are not paid carers, by establishing natural supports within the workplace.

The *framework for supported employment* states that:

As a matter of principle we start from the assumption that all disabled people may wish to access work, and that no individual or group should be assumed to be 'unemployable'. Supported employment transcends the traditional divides between 'vocational training' and employment-related supports; there is no assumption that potential workers have to be 'work-ready' before they can access supported employment. Embedded in our approach is the assumption that the best place to learn about work is in the workplace. (O'Bryan *et al*, 2000, p2)

Evidence has shown that the supported employment model works as a method of moving PWLD into non-segregated work environments, over less inclusive models such as sheltered factory environments or social firms with predominantly disabled employees (Beyer *et al*, 1996; O'Bryan *et al*, 2000).

For many, PWLD employment is only on a part time basis (DOH, 2001; Beyer *et al*, 2004; Emerson *et al*, 2005) and many other barriers to mainstream life still exist.

Barriers to mainstream living

The social model of disability provides a framework for helping to understand and respond to disability by providing a focus on the social, environmental and institutional barriers to social inclusion, that impact on the lives of people with impairments. Disabled people, including PWLD, have experienced wide-ranging social and environmental barriers to mainstream living in areas such as education, housing, transport, leisure, relationships, sexuality and employment that has led to their exclusion and segregation from mainstream society (Barnes and Mercer, 2005). The day-to-day lives of PWLD and their families have always been much affected by the way they are perceived and treated by the communities they live in.

It would be impossible to look in depth at all the barriers to mainstream living. It is important however to consider the effect of some of these barriers to help understand why some PWLD continue to use segregated facilities when they have part time employment.

As previously stated, research has shown that people with a range of disabilities want to work and would like support in employment but having the appropriate support to enable all aspects of independence and independent living are wanted alongside this (Beyer and Kilsby, 1997; DOH, 2001, 2007). As PWLD who have employment are most likely to have part time work, the many barriers to mainstream life will inevitably have an influence on what they do in the time when they are not in employment.

In reality, the long standing provision of group solutions to the individual needs of PWLD has contributed to the continuation of their segregation and social exclusion. If access to and appropriate personalised support was available to all, regardless of where or with whom they lived the problem may not be so great.

Person-centred approaches have been acknowledged as an important tool and a key element to help identify needs and aspirations, so that PWLD can develop ordinary patterns of adult life (McIntosh, 1998; DOH, 2005, 2007). For non disabled people, the ordinary pattern of life for people who work part time would not be to spend the rest of their time in segregated day services. It is particularly important that young people establish ordinary patterns of adult life, rather than getting caught up in traditional segregated services. One of the recommendations of *Valuing People Now* is that no young person leaving school and college in the future goes into a **segregated** day service or centre (DOH, 2007, p.31).

Valuing People Now: From progress to transformation identified that:

‘too many people are still receiving traditional services rather than being supported to live the life they want. People having the choice and control over their own lives and services is the starting point for *Valuing People Now*’ (DOH, 2007, p.7).

One of the largest most comprehensive evaluations of the costs and impact of person-centred planning to be undertaken anywhere in the world, reported on the impact of person-centred planning on

the life experience of almost one hundred people. It concluded that person-centred planning does enhance people's community involvement, contact with friends and family and choice (Robertson *et al*, 2005).

The Prime Minister's Strategy Unit document *Improving the Life Chances of Disabled People* (Cabinet Office, 2005) placed a new importance on informing, consulting and involving people who use health and social services and recommended that 'by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and be respected and included as equal members of society'. It also supported the development of direct payments and individual budgets, greater choice, improved transition arrangements, and improved support and incentives for disabled people to get, and stay, in employment (Cabinet Office, 2005, p.7).

The *Community Care (Direct Payments) Act* 1996 in the UK gave disabled people the legal right to receive payment of community care monies and to purchase their own care based on an agreed needs-led assessment. *Independence, Well-being and Choice* (DOH, 2005a) brought individual budgets and self-assessment into the mainstream of social care policy for adults and research has shown that direct payments can help people to gain confidence, develop new skills and access more individualised packages of support (Holman and Bewley, 1999).

On this island however direct payments and UK Government legislation does not apply although the island does aspire to national legislation, policy and guidelines as best practice.

Conclusion

It is clear that for many PWLD, choices are restricted not so much by their impairments as by the ethos and structures of the services that are available for them to use and that for many access has only been available to a restricted range of services (Riddell *et al*, 1999).

There was, and still is, much uncertainty about the aims and role of *day services*, with wide variations of what people actually do in them (Simons & Watson, 1999). Until the focus changes from traditional *day centre based* services, to the successful provision of *community-based day activities/day services* which are no longer *only* provided in centres, many PWLD will *remain* in day time provision, which is mostly based around group containment and 'occupation', and will not facilitate what needs to happen so that people 'have a good day' (Wertheimer, 1996; Clark, 2001).

Many local authorities are still struggling to move away from large congregate settings where development is affected by the local, social, political, economic and demographic circumstances.

PWLD like and dislike work for much the same reasons as everybody else and are more likely to be employed on a part time basis. They want to be supported to live the lives they want as

equal citizens in their community, with rights, independence, choice and inclusion.

Organisational and structural barriers have excluded many people with the label of learning difficulty from getting the appropriate support they need to meet their individual needs and person centered planning is essential to gaining appropriate personalised support to lead an ordinary life. Personalisation, where people have real choice and control over their lives and services through individual budgets, direct payments and person-centred planning has been identified in *Valuing People Now: From progress to transformation* as one of the five priorities for the next three years.

Chapter 3: Methodology

Introduction

In the introduction to this study I outlined the objectives of the research. In this chapter I will demonstrate that in order to achieve the previously stated objectives, I have used both theoretical and empirical methodologies. Data collection involved qualitative research methodologies including analysis of relevant literature, focus groups, interviews, and critical evaluation.

Research approaches recognise that our conceptions of the world shape the very nature of the world (theories) to be investigated. They have key implications for the methods that are used to investigate it and are a central part of the social sciences (Oliver, 2005).

Social research has, up until relatively recently, been dominated by the positivist paradigm. It is associated with quantitative research techniques and is generally used to refer to:

any sociological approach which operates on the general assumption that the methods of natural science (e.g. measurement, search for general laws, etc.) can be carried over into the social sciences (Jary and Jary, 2000, p.474).

The choice of methodology for this project is founded on data collection through qualitative interviews which are broadly grounded within an interpretivist approach and therefore rejects as inappropriate the quantitative approach of positivism. It is concerned with 'how the social world is interpreted, understood, experienced or produced' (Mason, 1996, p.4). The choice has

been made as the most appropriate in relation to the topic being researched, the number and kinds of people to be interviewed and the time allowed for the research to be undertaken.

Background and methodology

Much has been written about the role of disabled people in research (Barnes, 1996; Barnes and Mercer, 1997; Oliver, 1997; Walmsley, 2001). It was not until the latter part of the twentieth century however that PWLD were involved as more than just research subjects or respondents and there are now more studies that involve PWLD as informants (Goodley, 1996; Walmsley, 2001; Burke *et al*, 2003).

The aim of this research is to give voice and understanding to the experiences and priorities of people with a learning difficulty, so that the outcome of the research will directly benefit the informants. As Zarb states, disability research can only be said to be transformative to the extent that disabled people are able to *use* such research as an aid to bringing about changes in the status quo (Zarb cited in Barnes & Mercer, 1997). As stated earlier, the study aims to produce and disseminate the findings, after the research has been completed, in a variety of accessible formats, to PWLD, parents, carers, professionals and senior managers within the local Health and Social Services Department to inform practice, initiate further debate and bring about change.

The informants in this study have had the research topic chosen for them due to the time constraints and the fact that the research

will be used as part of an M.A. in Disability Studies for the researcher. The topic was, however, generated by observation of how individuals within the employment service continue to attend the workshop base even when they have obtained part time employment. It is informed by discussions that have taken place with users of the employment service about the choices, or control, they have in their daytime activities or services.

The research cannot therefore be emancipatory, which could be seen as a weakness but by using principles from both participatory and emancipatory disability research paradigms, the research was approached with a commitment to using methodologies appropriate to the participation of PWLD. Consideration was given to the key ontological claims for emancipatory disability research of trust, respect, participation and reciprocity (Oliver, 1992, p.107). Along with the participatory research principles and methodology of involving PWLD in the research process, qualitative methods were employed, with the aim of interpreting and explaining the experiences of PWLD.

Sample

The sample was purposive, using people who were relevant and significant to the study subject and was selected as the most effective for addressing the research objectives, as they relate to particular individuals, groups and this island setting. Denzin and Lincoln (1994) identify the attraction of a 'purposive sample in which selection begins with an identification of 'groups, settings, and individuals where (and for whom) the processes being studied

are most likely to occur' (Denzin and Lincoln 1994, p.202). Given my epistemology and the subject to be explored, the 'population' from which to sample and acquire the evidence was limited to and influenced by the need to identify key informants on the island who have the particular knowledge and experience to be evaluated. Five sample groups were identified through purposive sampling methods.

Here on the island at present, 36 adults with a learning difficulty attend the employment service 'workshop base' (WB), some people may use a combination of the WB and the 'day centre base' (11 out of 36), whilst some attend the WB on a part time basis and do not use the day centre base at all (9 out of 36). Others have been supported to gain part time paid contracted employment and continue to attend the WB and may also attend the day centre or local college of further education (9 out of 36). At present these nine service users who have been supported in obtaining part time work and who continue to attend the WB represent 25% of the 36 people attending. See table 1 in Appendix 7 for demographics of service users of community day services including the WB.

Approximately 100 disabled people are employed with the support of the Supported Employment Scheme. Of these, 36 people work up to 20 hours, 17 work 21-30 hours and 47 work over 30 hours. 50 out of the 100 have a learning difficulty.

For the purposes of the informants in this study I have included people who work up to 20 hours as part time and all the informants worked between 12 and 20 hours per week. Although there is no minimum wage on this island, all the informants are paid above the UK national minimum wage.

Table 2 in Appendix 8, shows details of the age, sex, hours and days worked and domicile of the informants.

Group 1

The study looked at the group of people who have been supported to gain part time work but continue to attend the WB to examine and evaluate the reasons why they continue to attend and not pursue other activities at the times they are not employed. A sample of three people was chosen from this group and included a mix of gender and age. The sample used people who work on more than two days a week and who had attended the WB for at least one year as part of the criteria.

Group 2

Included in group 2 was a sample of three PWLD who had previously attended the WB within the last five years, before being supported to gain part-time employment and who chose not to attend anymore. This helped to examine the reasons why they pursued other daytime activities on the days they were not employed and did not continue to attend the WB. The research aimed to establish what had influenced their choices and decisions. This sample of three people also had a mix of gender and age.

Groups 3 & 4

The parents/carers of the informants in the sample groups 1 and 2 or residential support staff, were included in this sample. They will be known as group 3 and 4 respectively.

Group 5

All the current staff of the employment service was included in this group.

Interviewing

I conducted nine qualitative interviews for this research. These were broken down into six individual interviews and three focus group interviews.

Qualitative interviews can generate insights into people's experiences, views and understanding as the topics are related to the everyday lived world of the informants and their relation to it.

Mason (1996) states that:

Ontologically, the qualitative interview is based on an assumption that regards people's views, understandings and experiences as meaningful properties of social reality, and the primary sources of knowledge of people's everyday lives. The qualitative interview encourages a more open and reflective relationship between the informants, and generates a deeper and more valid and reliable understanding of the social world (Mason 1996, cited in Mercer and Barnes 2005 Mod. 4 unit 4:9).

The qualitative nature of the research allowed for the collection of data from the perspective of the informants own interpretation, understanding and experience in their own words.

Individual interviews

The interviews were approached in stages. This involved initial meetings to outline, explain and discuss the research, including consent issues in taking part in the research and the recording of the interviews. Consideration was given to question type; wording, length and order (Mason, 1996; May, 1997). Piloting of the questions was carried out with two PWLD who worked part time but were not included in the sample, and valuable comments concerning the order, understanding and type of questions along with any difficulties experienced in answering them were taken into consideration. Individual interviews with informants in both group 1 and group 2 took place, followed by a further meeting to go through the typed transcript of the interview. This gave the opportunity for the informants to check and agree with what had been recorded. The final stage after the completion of the research will involve a meeting to discuss the findings and plans for dissemination.

Semi structured interviews were chosen in preference to structured interviews in order that informants would feel less constrained by a uniform, set, rigid structure of questions with a limited range of answers, that must fit into boxes or categories that had been predetermined by the researcher (May, 1997, p.110 & 113). This was seen as the most appropriate method of data collection due to the topic being researched and the type of informants and allowed for prompting, if needed, to obtain more explanation and information of people's views, understandings and experiences by means of a 'guided conversation' (Hall, 1996,

p.516) and for what Burgess (1994) calls 'a conversation with a purpose'.

The one-to-one interview was chosen in order to enable the informants to talk about topics they have lived knowledge of. It is one of the approaches favored in qualitative methodology because it adopts the interpretive paradigm of attempting to build an explanatory theory about the data it has collected through interactions with interviewees by focusing on why or how something is the case (Punch, 1998).

The interview process, as an interaction between the interviewer and the interviewee, needed to take into account the relationship between the two. Although both I and the informants in groups 1 and 2 had the advantage of knowing each other professionally, I was aware that the relationship was partially built upon my managerial position in the service that they were using. This could therefore be seen as both an advantage and a disadvantage, as I may be perceived primarily in this managerial role during the interview process. This was addressed during initial meetings with the informants when explaining about the research. The informants were offered the option of having the Advocacy Worker present at any stage during the research process, although no one took up this offer.

The appropriateness of the location where the interview took place was also considered. Although it would be easy to use the WB for the interviews, it was felt that it could evoke a more formal

atmosphere, where the association of my managerial role within the building could affect and inhibit the openness of the informants within that setting. The option of meeting in a room at the community centre or in their home was given. For some, however, the familiarity of the WB was the preferred location.

Focus groups

Group interview methods - 'focus groups', were used for groups 3, 4 and 5, who were invited to discuss the topic using a basic agenda. The questions asked of the group informants were not identical to those used for the individual informants but did parallel them. The groups were encouraged to discuss the matter freely in the hope that valuable information, opinions and attitudes would be brought out through the spontaneity and dynamics of the group.

Although it is acknowledged that a disadvantage of this type of interview is that it can encounter difficulties in arranging mutually acceptable times for all the informants, due to time constraints, it was deemed the most appropriate for gaining information as I could, as the researcher, collect qualitative data from a number of people at one time.

The optimum size of focus groups is founded on what May (1997) calls 'striking a balance between making the group too small for interactive study or too large for general participation' (May, 1997, p.113). It was anticipated that the size of the groups could vary, depending on whether one or two parents, or one or two support staff from groups 3 and 4, attended but I expected them to be

between 4 and 12. This would help me to make sure the discussion remained on the relevant topic and intervene only when required to bring the discussion back to the point (Stewart and Shamdasani, 1990). Five parents and support staff attended the focus group for group 3 and only two attended group 4. Two of the informants in group 2 lived in Supported Living accommodation that was supported by the same staff team and only one member of staff attended the focus group along with one parent of the other informant. The focus group with the staff of the employment service took place on a planning day that had already been arranged which made it easier to meet with all the staff as the whole staff group was available on that day.

The discussions of all interviews were recorded on a digital voice recorder to be typed up later and agreement to use this was sought before the interviews took place. Using a digital voice recorder to document the informant's views allowed the researcher to concentrate on actively listening rather than trying to make notes during the conversation.

Although the individual informants and members of the focus groups may not be regarded as representative of the population as a whole, the focus of the study was not to provide quantitative data but to provide qualitative insights and explorations in relation to the research questions and to highlight emerging issues and themes. The coding and analysis of the data will be discussed in chapter four.

Ethical considerations

This research was considered by the local Health and Social Services Ethical Committee which sets out rules for the proper conduct and documentation of research studies involving human subjects.

Gaining informed consent was an important consideration. The principle of informed consent is seemingly straightforward where the research subjects have the right to make a voluntary decision of whether or not to take part in the research. It requires the decision to be 'informed' by an understanding of what the research will entail and requires the 'capacity' to consent.

The issue of consent was reaffirmed during the interview process if the open nature of the semi structured interview lead to areas that may not have been expected to be pursued. Informed consent should not simply be contracted at the outset; therefore issues of consent were reiterated and re-affirmed throughout the research process to allow people the opportunity to change their minds (Miller and Bell, 2002).

When undertaking research with PWLD, it should not be assumed that they are unable to make their own decisions simply because they have a learning difficulty. Particular attention was paid to discussing the purpose and implications of the research and checked that these had been understood. Careful consideration was given to the use of language and any documentation or consent forms were appropriate and accessible. See Appendix 2 &

Appendix 3 for examples of the information sheet and consent forms.

Ethical concerns relating to anonymity and confidentiality were discussed along with the purpose of the research. The informant's real names have not been used in this study although acknowledgement for taking part was offered. The data from the recorded interviews was stored securely and it was explained who was likely to read the research documents and who would have access to the material including the typing up of the transcripts.

Dissemination

The dissemination of the research findings must be as accessible as possible to both the research informants and to relevant audiences (Mercer & Barnes, 2005). The preferred way of dissemination will be discussed with the informants as this could take several forms. Producing summary leaflets to provide a succinct and easily accessible overview of the research findings is one option. It is planned to have face to face meetings with the informants as well as producing summary leaflets using plain language along with graphics, similar to *Plain Facts* (Norah Fry Research Centre) which produce summary leaflets of research findings that are no more than 650 words long, or longer than four A4 pages.

If the research is to be of any value then the communication of the research findings to the most appropriate people in the local Health and Social Services Department is imperative. The findings will be presented, in partnership with some of the informants who

are willing to take on this role, to the senior managers and the Professional Advisory Group for the adult disability service. This could be challenging to the audience because of both the content raised and the empowerment of the PWLD.

Conclusion

This chapter has examined the process of research design for this study. It has outlined the main phases of the fieldwork undertaken over the period of five months and has included discussion of the strengths and weaknesses of the chosen methods. The next chapter will examine the results obtained from people in groups one and two and will include a description of the steps taken in data analysis and interpretation of the data.

Chapter Four: Day services, employment and somewhere to go? User's views.

This chapter examines the information obtained from the accounts of PWLD and includes a discussion of the steps taken in the data analysis.

Analytical procedure-thematic analysis

Following the initial meetings and interviews a second meeting was conducted with the informants to go through the full transcripts of the interviews to confirm that what had been discussed during the interviews had been recorded correctly. After transcription of the interview material the data was organised thematically, initially as quite broad categories. The initial familiarisation and immersion with the data throughout the data collection procedures helped to get a feeling for the overall meaning of the data which aimed to discover the opinions and experiences of the informants and explain the reasons why some PWLD continue to use segregated employment services when they have part time employment.

The design and steps involved in conducting a content analysis are well established (Bauer, 2000), however there are surprisingly few published guidelines detailing a protocol for carrying out a thematic analysis and it is often used in published studies without a clear report of the specific techniques employed (Marks & Yardley, 2004, p.58).

In this project the following protocol was developed by considering the recommendations of Marks and Yardley (2004).

1. The transcripts were read and re-read a number of times and notes made in the margin to reveal some of the possible emerging themes.
2. Coding processes were then developed to note and label patterns in the data from the individuals transcribed account. The codes where possible referred to the manifest content of the data, that is, something directly observable in the text. Latent level codes were also assigned where the content was implicitly referred to and all codes were established from the raw data itself.
3. These sets of codes were developed into the coding frame. The codes were listed by their labels, grouped under higher level categories (Super-code) then sub-divided into lower level sub-categories (Sub-code) with explicit examples being illustrated through excerpts from the text.
4. As the codes emerged the categories were refined through splitting, splicing and linking.
5. 'Test-retest' reliability was used in order to increase reliability. The researcher applied the codes to the same text on two occasions after a period of at least a week after the initial coding.

The analysis revealed the emergence of a number of themes in each of the interviews that were grouped together into a number of 'super-codes'. The coding frame was developed by drawing all the themes together from all of the interviews as it became evident

that many of the codes ran through each of the participant's narratives. 'Sub-codes' were developed and it emerged that complex interactions existed between the super-codes and particular sub-codes that were linked to other sub-codes of different clusters or super-codes.

The super-codes were divided into three broad categories *organisational aspects*, *social aspects* and *reasons for staying/not staying at the WB*. Each of the super-codes will be explained below in terms of the range of sub-codes it encompasses.

There were also some issues relating to the reliability of the data that need to be briefly mentioned. Some informants did not discuss a topic in detail, or not at all, particularly by saying "I don't know" or "not sure". It was difficult, for example, to determine whether responses accurately reflected the informant's experiences. It may have been because they had not fully understood the question, it wasn't important or significant to them or they simply could not remember or genuinely did not know. For some the more formal set up of the interview meeting may have affected the reliability of the data.

Organisational aspects

The way that day and employment services were developed and are organised on this island made it difficult to relate directly to research carried out in the UK as the employment service in fact incorporates elements of the "models" of a *sheltered workshop*,

day centre and *supported employment* agency and regarded as part of day services.

Sheltered workshops have provided occupation but as previously identified, by being 'sheltered', this has excluded them from being inclusive or progressive (O'Bryan *et al*, 2000). All the informants in this study did 'attend' the WB prior, to being supported into employment. This appears to have contributed to the reason for some of them continuing to use segregated facilities even when part time employment in mainstream settings was found.

The WB has, however, also allowed for effective work skills training and preparation and provided staff support on a one to one basis for work experience placements, work trials and in-work support. This support can be given to PWLD who work only a few hours and it has helped as a stepping stone for some people to consider taking on more hours of work. It is not just a sheltered workshop but has employment as a clear target.

Under the super-code 'organisational aspects' a number of sub-codes were identified; what the role of the WB was seen as - to help find a job, seen as work, work experience, stepping stone, somewhere to go, place to meet friends, attendance allowance and length of time appropriate to stay at the WB. Examples of the codes that constitute the super-code "organisational aspects" are given in table 3a & 3b, Appendix 9.

The role of the workshop base

I was interested in finding out what information informants had about the employment service before attending the WB and what they thought it was for, to see if it had any influence on their reasons for continuing or not continuing to attend the WB.

The informants gave varying opinions of how they acquired the information and knowledge and what they thought they WB was for. Some were unsure about what they knew and understood about it before attending.

The WB was directly mentioned by all the informants as helping them to find and keep part time employment. Doing work experience was mentioned as an important role and work experience had been done by all the informants before taking up contracted part time employment. This was valued and seen as a 'stepping stone' into employment. F2 informed me that she was given information "about the workshop and employment and the Supported Employment Scheme". Both F1 and F2 both stated that they had come on a work experience placement when they were at school and that it had helped to "get to know people".

Some had also started off with a small amount of employment hours and had increased the amount or got other part time jobs after being successful in their first job. M3 for example, had not initially wanted to leave the WB at all but after seeing other people trying work experience and commenting positively he tried it himself and now has three part time jobs. This showed that for

some the experience of attending the WB provided 'living examples' of PWLD being successful in work experience and employment.

Two of the informants, M3 and M4, could not remember how they found out about the WB or what information they had been given before attending, although they were able to give an opinion on what the WB was for and that it had supported them to find employment.

M2 said he thought the WB was to do different jobs for different firms and also thought it was so that people could keep in touch with friends and just for a change of work, "I see it as an extra" and "an excuse to see how people are getting on".

The desirability of locating future support in community settings is clearly favorable to the potentially prejudicial effects of segregated support. For some, however, the WB clearly provided a 'stepping stone' from the 'safe places' and networks that had become important to them.

Some people included meeting up with and chatting to friends as a reason why they liked attending the WB. M3 and M4 missed seeing their friends at the WB but did not want to come back. It was not surprising that some of the informants valued the WB as a place to meet friends. Networks and relationships had been built with people that they had had known for a long time both at the WB and in other segregated settings such as school or the day centre, which were implied as being seen by them as 'safe

spaces'. Research has shown that some people do find it difficult to let go of the segregated places and relationships that they have developed (Simmons & Watson 1999).

The WB was directly mentioned by two people as a place to help people get other employment but was also viewed as 'work itself' by some of the informants. When part time employment was found they continued doing this 'work' as well. F1, thought it was "a place to work, a change of work, do more work" alongside her part time employment. M1 stated he saw it as work and because "it gives me something to do and it's what I can cope with", "I like doing the variety of work down there" and also mentioned that service users should stay "as long as they want to really".

A couple of people mentioned that the attendance allowance they received was important to them; "I come so I can get my attendance money".

For some it was just seen as a place to go and have something to do. M1 thought it was "to give people something to do with their day" and others said it was "somewhere to go".

When the WB was developed it was seen by a few as an alternative place to go other than the day centre. The emphasis initially was on providing 'work' or 'occupation' in a sheltered setting. Supporting people into employment in mainstream settings became more of an emphasis as the employment service developed.

All of the informants did not want to go to the day centre as they wanted to occupy their time in a work setting and saw attending the WB as “preferable to going to the day centre”. Three people had attended the day centre prior to attending the WB. They were not doing so however when they were supported to find part time employment.

Length of time appropriate to stay at the workshop base

There was no clear understanding of how long people thought they should be able to stay at the WB, with some informants stating that people should be able to attend as long as they wanted, even if they did have employment. None of the informants could recall discussions about continuing or not continuing to attend, prior to, or upon being supported to find part time employment. No one could remember discussions taking place at this time about alternatives or other things that could be done on the days that they were not working.

Attending the WB on more days than employment is taken on, appeared to be an important element in whether people continued when employment was found. Both M3 and M4 had attended the WB on a full time basis prior to obtaining part time employment and both had initially continued to attend on the times they were not employed. They did however stop attending a short while after they obtained employment.

F1 and F2 had clearly seen the WB as a place to support them into employment and not a place to stay for a long time. They are both under 25 and their expectations of obtaining employment and

not continuing at the WB differed from the older informants. In contrast M1 and M2 thought people should stay as long as they wanted and had indeed continued to attend.

Social aspects

Under the super-code 'social aspects' a number of sub-codes were identified; General social activities - with work colleagues, with friends, with family, in the evenings/weekends, Community activities, Routine activities. Examples of the codes that constitute the super-code 'social aspects' are given in table 4a & 4b, Appendix 10.

Supported employment takes place in integrated settings where the emphasis is on contacts and relationships with work colleagues who are not paid support staff or carers. When the informants were asked if they met up with work colleagues outside of work, the majority of the informants said they did not meet up with them except for "occasional work do's or Christmas parties". This was consistent with all the informants whether they continued to attend the workshop or not. M3 who had worked part time in one job for twenty years said he did not meet up with people outside of work. M1 stated he saw people at work as "friends at work, not out of work". All the informants enjoyed the social contact they had with work colleagues where they were employed, even if they did not transfer their work acquaintances into regular friendships outside of work.

Some commented that they valued the long term friendships they had with friends they had known a long time. F2 stated “most Fridays I go and see a friend, we have known each other since we were three, went to the same school”. She also pointed out that the people she worked with were older than her and she didn’t really want to have friendships with them out of work.

The variety of social activities that the informants were involved in when they were not working was very similar. People from both groups attended clubs with other disabled people.

Two people who had stopped attending the WB however, did do more things independently than those who continued to attend. These included shopping, going for a walk, going to the library and gardening. One of the reasons given for not attending anymore was that ‘supported living’ had supported them to do the things they wanted to do and had also helped them to understand that it was okay to be at home. F2 had also been supported by her family to keep in contact with friends, go swimming, attend a fitness class and had help with lifts when required; “I go to meals out, the theatre, leisure centre, swimming”.

Reasons for staying / not staying at the workshop base

Under the super-code ‘Reasons for staying / not staying at the WB’ a number of sub-codes were identified; Reasons for staying at the WB - discussion or information about alternatives, something to do, attendance allowance, place to meet friends, no perceived

time limit, seen as work, had attended WB on full time basis / or more days than part time employment, seen as a 'stepping stone', seen as a waiting place, life plan, preferable to 'day centre', support to do other things.

Reasons for not staying at the WB - Found a job, stepping stone, enjoyed doing other things, support to do other things, supported living, Attended the WB on a part time basis, no intention of staying, life plan, discussion or information about alternatives. Examples of the codes that constitute the super-code 'Reasons for staying / not staying at the WB' are given in tables 5a, 5b, 5c & 5d in Appendix 11.

The informants gave specific insights and reasons for staying or not staying at the WB and these were varied, some of which have already been mentioned.

Reasons for staying

The age of the informants and length of time they had been attending the WB did appear to have an effect on their reasons for staying. Both M1 and M2 enjoyed seeing their friends and saw it as a place to do other work, different to their paid employment but also liked getting the attendance allowance money.

M1, who lives in shared residential accommodation, had attended the WB on a full time basis prior to being supported through work experience and on the job support to secure part time employment. The job was initially three mornings and one full day

and he had “just continued to attend on the afternoons and the day he was not in his other job”. Recently M1 has changed his hours to work every morning and following discussions has decided to take one afternoon off and not attend the WB.

M2, who lives with his parents, has been in part time employment in one of his jobs for over 20 years, prior to attending the WB he attended the Adult Training Centre. He was able to tell me he had attended there from 1978 – 2002. When he had been supported to get some other part time work, he still continued to attend the WB on the days he was not in paid employment. He stated he had had a life plan a long time ago but that was when he attended the centre.

As previously stated both M1 and M2 saw attendance at the WB as preferable to the alternative of attending the day centre but had not discussed or really thought about other alternatives. For them the key issue was that the WB provided the more positive social status of a ‘workplace’ and being a ‘worker’. When asked if they could think of anything else they could do on the days they were not working M2 did say “I’d like to be able to go to a gym, if I could get help just for a month, to build it up, then I could perhaps carry on” and also would consider more work but thought it might affect his benefits. M1 said he hadn’t really considered it, but would consider doing other things “if it was something I could cope with”. He could not remember talking about alternatives at his life plan. They did not see the day centre as the place to go to get the support to do other things.

F1 had seen the employment base as more of a 'waiting place' until she had felt more confident to move on and during the duration of the research had in fact gained more hours of employment and left the WB. She did not know what Life Plans were.

Reasons for not staying

As previously stated M3 and M4 had attended the WB on a full time basis prior to obtaining part time employment and had initially continued to attend on the times they were not employed. They had been supported by the staff where they lived to understand that they did not need to attend the WB anymore if they did not want too and were supported to do other things; "I stopped coming because I could". "I enjoyed staying at home and watching the telly or going for a walk, I could do that when I moved to Supported Living". They could not remember whether they talked about this as part of their life plan. M4 said he enjoyed "putting things in envelopes and missed coming to the WB but did not want to come back" and "wanted to work more hours now if he could".

F2 had no intention of staying at the WB and had support from her parents to do other things on the days she was not working; "I didn't want to stay; I just wanted help to get a job". "I don't want to work any more hours than I am doing and my Mum helps me to do things when I am not working". She had also only attended on a part time basis before employment was found. F2 had not had a life plan and identified that it would be good to get a bit of support

from someone other than her mother and identified that transport may be one of the areas where she may need support.

Conclusion

I had initially expected to discover reasons related to the way day and employment services were organised which may have affected the informant's reasons for continuing to use segregated services. It became apparent however that these reasons also related to lack of discussion, information or understanding of the possible options or choices that were available at key life stages including when part time employment was obtained. This meant that support requirements in other areas of their lives in order to be able to choose or be supported to do other things during the time they were not working, were not necessarily considered or planned for, by them, their parents, carers, the employment service or the Health and Social Service Department, before or upon, the take up of part time employment.

There was no clear understanding of how long people thought they should be able to stay at the WB and none of the informants stated that they could recall any discussions prior to or upon being supported to find part time employment about continuing or not continuing to attend.

It is clear that organisational and structural barriers have excluded people with the label of learning difficulty from getting the appropriate support they need to meet their *individual* needs and

interests (Cole *et al*, 2007), particularly when part time employment is found.

The relationships that were built in the long standing provision of group solutions to individual needs, has contributed to some, still spending some of their time in a segregated setting even when they have employment in mainstream settings. It was clear however that the younger informants did have greater expectations of leading an ordinary life and had only seen the WB as a 'stepping stone' into employment with no intention of staying at the WB.

The opportunity to have a "Life Plan" has not been available for *some* PWLD who are on this islands' 'Adult Learning Disability Register'. This includes those who *do not* access either the day *centre service* or other parts of the residential or Supported Living service and who *only* attend the WB or are in employment.

People having the choice and control over their own lives and services is the starting point for *Valuing People Now* (DOH, 2007, p.7). Personalisation including person centered planning is essential in *all* aspects of life in order to enable PWLD to; 'have a good day', access community services and lead an ordinary life.

Chapter Five: Day services, employment and somewhere to go? Parents / Carers views.

Introduction

This chapter examines the information obtained from the accounts of parents, carers and the employment service staff in groups 3, 4 and 5 and compares and contrasts with the views of service users. I will refer to these groups as parents, carers and employment staff.

The coding frame was developed using the same format as the service users revealing the emergence of a number of themes in each of the interviews that were grouped together into the 'super-codes'.

The super-codes were divided into the same three broad categories *organisational aspects*, *social aspects* and *reasons for staying/not staying at the WB*. Each of the super-codes will be explained below in terms of the range of sub-codes it encompasses.

Organisational aspects of services

Under the super-code 'organisational aspects' a number of sub-codes were identified; what the role of the WB was seen as - to help find a job, seen as work, work experience, stepping stone, somewhere to go, place to meet friends, attendance allowance and length of time appropriate to stay at the WB. Examples of the

codes that constitute the super-code 'organisational aspects' are given in tables 6a & 6b, Appendix 12.

The parents and carers supported the views of service users that the role of the WB included providing support for work experience and that it was valued as a 'stepping stone' into employment. They agreed that it helped people to find and keep employment and that staff support had been important part in this.

M2's parents stated that it was difficult to say how they had found out about the WB but said the day centre was there first and it was something that came after, as people wanted to get more work. They stated that things have gradually changed because "at one time there was no expectation that people would move on from the day centre and get a job" and also M2 "did not have the opportunity to go to college after leaving school like they do now". They also acknowledged that as M2 was older it had become a habit to attend the centre or WB and he had just carried on. "His friends didn't go to work and he wanted to keep in touch with them, people his own age".

F1's parents found out about it through school. They stated that "the whole system had worked beautifully" for F1. "It's worked beautifully to build up her confidence". She tried the job on work experience first and was then employed for three half days. "She started off with being supported by staff, which was perfect for her. At one time she was offered a full time post but we decided that it would be too brave a move". Although they did not see the WB as a place to stay, they thought people should stay as long as they wanted. They saw the WB as giving people "something to do in the

meantime” while they were waiting to find employment and also for staff “to find out how they can cope”.

Some parents and carers felt that service users, parents and carers needed more detailed information about all the different elements of the employment service.

One of the employment staff mentioned that the role of the WB had changed over the years; “From when we first started it, it’s changed, the whole role has changed”. Some employment staff agreed that they were unsure whether all of the service users, parents and carers were aware of this. The employment staff also agreed that the older service users looked at things differently to the younger group who had more of an expectation of finding employment and not staying at the WB; “so it’s more of a ‘stepping stone’ if you like”.

One of the employment staff also mentioned that he felt one person who had a few part time jobs only came to the WB to “fill in the time”. Some employment staff thought that some service users who lived in the residential service may have attended to occupy their time without having an employment need.

Length of time appropriate to stay at the workshop base

These groups also agreed with the service users views that there was no clear understanding of how long people thought they should be able to stay at the WB, with some of them also stating that people should be able to attend as long as they wanted, even

if they did have employment. M2's parents thought "he may feel that he was being 'sacked' if he couldn't go anymore". They also thought that "he had become institutionalised and was still using segregated services but we must stop it happening to younger people".

The majority of the parents and carers could not recall discussions about the service users continuing or not continuing to attend, prior to, or upon being supported to find part time employment. They also could not remember discussions taking place at this time about alternatives or other things that could be done on the days that they were not working.

The staff member from Supported Living thought that M3 and M4 "did not realise at first that they didn't *need* to go to the WB anymore when they got their part time employment". "They didn't realise at first that they had the choice".

Some employment staff felt that it wasn't clear to them either. One member of staff commented that if a person no longer attended the WB on certain days it could have issues for the carers or other parts of the service. They also felt that because it would have issues for all of them, some parts of the service may not want it to happen.

The employment staff agreed that people should be supported to lead 'ordinary lives'. They mentioned a long list of things, that people who they knew, who worked part time, did when they were not working, these included; housework, shopping, just being at

home, going out in their boat, visiting people, reading, gardening, swimming and socialising. They identified that for PWLD to lead an ordinary life and do some of these things, some people may need some *support*.

If it meant that service users continued to attend a segregated congregate service when they were not working, because they were not getting the support to meet their individual needs, the employment staff thought there was a gap in the service.

Social aspects

Under the super-code 'social aspects' a number of sub-codes were identified; General social activities - with work colleagues, with friends, with family, in the evenings/weekends, Community activities, Routine activities. Examples of the codes that constitute the super-code 'social aspects' are given in tables 7a & 7b, Appendix 13.

Parents and carers supported the view that the informants only met up with work colleagues outside of work for the "occasional work do's or Christmas parties"; "Only at functions". "No, except for Christmas, they are friendly enough whilst she's there".

Some mentioned that being employed helped to "expand contacts" and "helps in terms of the circle of people they know".

Parents and carers agreed that the service users did value the long term friendships that they had with friends they had known a

long time. F1's parents said that she went out with friends from college who were her own age.

The variety of social activities that the informants were involved in, when they were not working, were affirmed by the carers and parents.

F2's mother confirmed that they did a lot of things together as well as F2 meeting up with her friends and befriender. She stated that she had to do a lot of the running around and although it was okay at the moment she may not want to be doing that in another ten years time. "F2 may want a bit of support; although we manage at the moment her support needs may change". "We don't get any support apart from when she is working". "F2 has not had a life plan and we have not really had the opportunity to sit down and talk about needs".

The carer from Supported Living acknowledged that M3 and M4 did "the same as everyone else who works part time really, go for a walk, use the buses, library, visit people, shopping". She pointed out that money and transport may restrict some things that people want to do but that this could be the same as others in part time employment.

One carer stated that "I know a lot of them also, for lots of reasons, still want to have contact with the WB, possibly from the social set up – meeting up with people that they went to school with years ago, meeting new people, having a laugh, I think there's an element of that".

When the employment staff discussed what sort of help or support people might need to be able to do things on the days when they were not working, they thought the idea of 'evening support officers' as well as 'day service officers' could help.

Reasons for staying / not staying at the workshop base

Under the super-code 'Reasons for staying / not staying at the WB' a number of sub-codes were identified; Reasons for staying at the WB - discussion or information about alternatives, something to do, place to meet friends, no perceived time limit, seen as work, had attended WB on full time basis / or more days than part time employment, seen as a 'stepping stone', life plan, preferable to 'day centre', support to do other things. Reasons for not staying at the WB - Found a job, stepping stone, enjoyed doing other things, support to do other things, supported living, attended the WB on a part time basis, no intention of staying, life plan, discussion or information about alternatives. Examples of the codes that constitute the super-code 'Reasons for staying / not staying at the WB' are given in tables 8a, 8b, 8c & 8d in Appendix 14.

The informants gave specific insights and reasons why they thought service users stayed or did not stay at the WB and these were varied.

Reasons for staying

F1 had seen the WB as more of a 'waiting place' until she had felt more confident to move on. Her parents had also thought of it like that and wanted her to be as independent as possible; "We want her to be as independent as possible and working is part of that. Friends go to work as well"; "hopefully she won't stay if she can get full time employment when she is ready". They also thought that "society had changed and services must change as well".

M1 had been at the WB full time before he had obtained part time employment and when one of his carers had asked why he carried on going he had said "just because" and because he "liked it". She agreed that attending full time may influence the reason for carrying on at the WB when part time employment was found.

M2's father had stated previously that he had got into the habit of attending and just carried on. He also enjoyed seeing his friends at the WB "part is friends and also staff, he thinks of them as friends, he also likes helping others".

Some employment staff supported the view that some people carried on coming out of habit; "they've got into a set routine and they don't want to lose that". They also agreed that discussions did not take place prior to or upon being supported to find part time employment, about whether people could do other things when not working. Some felt it was not necessarily their own choice; they may not have even discussed it. Some employment staff felt it was because they don't have alternatives or were not aware of

alternatives and the support may not be in place to do anything else.

Reasons for not staying

The carer from Supported Living was clear that she did not think that M3 or M4 had realised initially that they didn't have to go to the WB. When they did realise that they had the choice they both stopped going. "We support them but we try and give them their independence and we give them the choice, that's the big word, choice". "They had a new found freedom with the change from residential to supported living". "M4 really enjoys his job and the time he is not working, he is always doing something; in town, gardening, going for a walk". M3 "goes to his dad's a lot and doesn't go out so much on his own; he walks to work and goes to the supermarket and he enjoys his jobs".

F2's mother felt that it was easy for her not to carry on as she had only attended on a part time basis; "that's what was available, then the job came. It worked out fine. She wouldn't think to come back now". "I think it is important that I can support her on the days she is not working". "She has enough hours so doesn't need support to get any more work at the moment".

Conclusion

Support to explore or use ordinary community services when not at work was an important aspect of not attending the WB. If support is available to people who work part time they may not

continue using segregated services. When part time employment was found, Supported Living had facilitated people to have the choice and control over their own lives, and ordinary lifestyles were able to develop and progress alongside this.

Clearly, if person centered planning and support to explore or use ordinary community services are available to people who work part time they may not continue using segregated services. This support was available for some from a variety of sources including Supported Living arrangements and family.

The collected data from the interviews indicated that segregated day and employment services were viewed as the only option when some of the older informants started to use day services. The emphasis had changed from people only doing sheltered work, to having employment as a clear goal. The expectation for some was that they would attend a segregated service and this legacy in effect has meant that some of the informants believed that having “somewhere to go” entailed being with other PWLD rather than being supported to lead an ordinary life. One of the consequences of spending years of their lives in segregated services is that people have low expectations of what can be achieved in their lives because they rely on a narrow range of people or support.

Valuing People (DOH, 2001) states that; “we must enable people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work” (Valuing People, 2001, p.84). The

employment service on the island successfully supports people to participate in all forms of employment, however when PWLD do get paid part time employment which makes a 'valued contribution' to the world of work, the choices and control over the rest of their life may be limited.

Chapter Six: Conclusion/ Summary

This research project aimed to provide informative insights into some of the reasons why PWLD on this island continue to use segregated employment training facilities when they have successfully accessed part time employment in a range of mainstream settings.

It raised the question:

‘Does the way that day and employment services are organised contribute to the continued use of segregated employment training facilities when PWLD have part time employment in mainstream settings?’

Research has shown that people do use both congregate centres and sheltered workshops if no other alternatives are available (Barnes, 1990; O’Byrne *et al*, 2000; DOH, 2001, 2007; Emerson *et al*, 2005; Scottish Executive, 2006).

Valuing People have made it clear that services should be helping people to achieve self determination, social inclusion and an ordinary life and evidence has shown that access to real paid work is most important to PWLD (DOH, 2001; 2005; 2007). The way local areas in the UK are organising services to support people to achieve this is very variable (DOH, 2005) and many local authorities are still struggling to move away from large congregate settings where development is affected by the local, social, political, economic and demographic circumstances (Cole *et al*, 2007).

Work is the main form of daytime activity for the majority of adults. It is liked and disliked by PWLD for much the same reasons as everybody else. It is aspired to and regarded as part of an ordinary life. Many PWLD however are employed on a part time basis (Beyer *et al*, 2004) and need support to have an ordinary life when they are not working.

Day services which embrace the paradigm shift of supporting people in community based day activities have the enormous potential of being a truly empowering force for PWLD. Organisational and structural barriers have excluded PWLD from getting the appropriate support they need to meet their *individual* needs and interests (Cole *et al*, 2007).

‘Having a good day’

In order for PWLD to take control of their own lives, gain independence and ‘have a good day’, person centered planning is critical. It has been shown to work (Robertson *et al*, 2005) and the importance of this approach for young people at the time of transition to adult services is particularly important to ensure that they do not get caught up in traditional segregated services and are able to establish ordinary patterns of adult life (DOH, 2007).

Doing things that have a purpose, being in ordinary places, doing things that most other members of the community would be doing, doing things that are right for you, receiving support that meets your needs, being in touch with local people, meeting people and developing friendships are all highlighted as elements needed for

PWLD to have an ordinary lifestyle and 'have a good day' (Cole *et al*, 2007, p.2).

This study showed that all the informants did indeed spend some time in ordinary places, did things that had a purpose, were in touch with local people, developed friendships, did things that other members of the community would be doing, did things that were right for them but for some this was not *every day*. Gaps existed in the support required to meet their individual needs and to lead an ordinary lifestyle which meant that some people continued to use segregated services even when they had part time employment in mainstream settings.

Although the employment needs of the informants were met through person centered planning using the supported employment model, Life Plans were not available to people who did not live in the Health and Social Services residential establishments, or attend the day *centre service*. Although Life Plans for this group of people has been recognised as an area that needs to be addressed, this does not currently take place. It is therefore vital that local services strive to find ways to enable PWLD to have the opportunity to explore possible alternatives to remaining at the WB, when part time employment is found.

Reasons for continuing to use segregated services

This study highlighted a number of reasons why some people who work part time continued to access segregated services on the days they were not employed. The decision to continue to use or not use the WB was influenced by a number of factors.

Historically, day services for PWLD have been developed and provided without any real *strategic* examination of their purposes and objectives. Day services have often been based on vague assumptions about "giving people something to do", without serious consideration of the long-term needs of individuals, carers or the wider community. The WB was used by some informants as 'somewhere to go' and 'something to do' when not working in their part time employment.

Although PWLD can access supported employment without attending the WB, all the informants in this study had been supported into employment after first attending the WB. This meant that some had just carried on attending on the days that they were not working in their part time employment and others who had spent a long time in segregated services found the WB hard to let go.

Another factor was that discussions, about continuing or not continuing to attend the WB, prior to, or upon being supported to find part time employment, did not take place or were not recalled by the informants, parents or carers. There was also no clear understanding of how long people thought they should stay at the WB. This was possibly due to the fact that the WB was part of the employment service which houses elements of a sheltered workshop, day service and supported employment.

There was a difference of attitude and expectation between the younger and older informants in relation to staying or not staying at the WB. Younger PWLD, and their parents, had expectations of them moving into employment and not staying in a segregated setting. They had not thought of the WB as somewhere to stay, more of a 'stepping stone' to provide work experience and subsequently enable them to acquire employment.

Support to do other things when not working was a crucial element in people not attending on the days they were not working. Support was given by parents and Supported Living staff for some of the informants. Supported Living played a big part in enabling two of the PWLD to lead an ordinary life by providing the opportunity to choose to do ordinary activities or stay at home on the days they were not working. Some PWLD and their parents requested *some* support for them to do other things in the community and acknowledged that the parents may not always be the best people to facilitate this or may have difficulties to providing it when they were older.

A couple of people who did continue to attend said that although they had not really thought about doing other things, they would be open to consider them, if they could get the support.

Although a small scale study, the findings from this project have highlighted areas where the choice and control over the informant's lives and the services and support they receive are at present limited by the services that are available to them. The way that services are organised has meant that PWLD have routinely

been expected to fit into existing services and historically these have been in congregate, segregated settings.

It is important that service providers recognise the need to consider the recommendations of *Valuing People Now* for personalisation and forward planning in *all* aspects of the lives of PWLD. The focus must now be on enabling PWLD to take control of their own lives, identify their needs and explore alternative solutions, thereby removing the dependency on sheltered and segregated environments.

The findings from this study will be produced in a variety of accessible formats and disseminated to PWLD, parents, carers, professionals and senior managers within the local Health and Social Services Department and it is hoped that this will initiate further debate on the issues raised by this study.

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Appendix 1

Background and research setting

The research took place on an island with a population of approximately 60,000 people which is one of the Crown Dependencies. As a Crown Dependency it is geographically part of the British Isles but is an autonomous state with a tenuous political link to the UK. The government of the United Kingdom in Westminster has no legal duty or responsibility with respect to the administration or running of Crown Dependencies except where agreed by international treaty.

The island therefore does not have the same laws as mainland UK and has very little legislation directly related to disabled people or discrimination. The UK Disability Discrimination Act 1995 for example does not apply on this island although the adult disability service does follow the National and International legislation, policy and guidelines as 'best practice'.

In the UK, daytime opportunities for PWLD have, until relatively recently, been provided in large usually segregated settings such as the adult training centre or social education centre, where contract work was often undertaken (e.g. basic assembly and packing) and people received a nominal payment or 'attendance allowance'. Other activities included basic skills, social skills, arts and crafts, leisure and recreational activities.

The development of Day Services for PWLD on the island basically followed the trend of the UK. Day Services started here,

with the creation of the day centre, in 1969 where, initially, the 'trainees' programme included industrial work e.g. assembling tomato boxes, flower boxes, nailing pin sticks, picture framing and letterpress printing. Further education, domestic science, art classes, gardening and sports activities were also an initial part of their programme. The centre along with the rest of the services for PWLD have changed and developed since this time. The expansion of 'community care' facilities including residential, respite, and allied professional services, the development of supported living, the employment service and the advocacy service have all helped to shape the service into what it has become today.

On this island the focus and activities of the day centre, until recently segregated on the hospital site, have changed, with more emphasis on activities out in the community. This part of the day service has recently moved to be based at and be part of a new community centre. In 1994, day services expanded to include a sheltered workshop for PWLD, which now forms part of the Employment Service. Although this was originally and still is, separate to the day centre this was and still is part of the Health and Social Services *day services*.

Initially this was set up to meet some of the employment needs of people with a learning difficulty by creating a 'sheltered work' environment separate to the day centre, I will refer to this part of the employment service as the 'workshop base' (WB). This has gradually expanded into a wider Employment Service for disabled adults including a range of employment opportunities. The

sheltered WB for PWLD provides work preparation, training, an opportunity to understand the work ethos and as a transition or stepping stone to other employment opportunities. This includes the setting up and facilitation of work experience placements, supported on a one to one basis, by Employment Support Officers, to enable service users to experience and try different jobs. The aim is to move into either full or part time, supported or open employment, with the amount of staff support being adjusted as the person feels comfortable in the job.

The employment service also includes a sheltered workshop for disabled adults with a range of impairments and cleaning team of supported employees who are contracted through the local Health and Social Services Department and are paid a wage through the Supported Employment Scheme.

The Supported Employment Scheme, which has a separate budget, is also part of the Employment Service. It aims to find and support people in gainful employment who by reason of their disability are unable to obtain employment in the open labour market. The scheme can subsidise the employer by paying a percentage of the wage, with the employee getting the going rate for the job. The percentage can be adjusted through reviews which take place regularly. At present approximately 100 disabled people on the island are employed with the support of the scheme, of these 50 have a learning difficulty.

Appendix 2

Information Sheet

- **My name is Wendy Tiplady. I would like your assistance with a research project I am working on for a Masters Degree in Disability Studies with Leeds University.**

What is the research about?

I would like to ask you about your ideas on why people with learning difficulties continue to come to XXXXXXXXX Services, when they have part time jobs.

What happens next?

When I've talked to you and some other people, I'll put all the information together. I will then write a report of the findings to tell people what we have found out.

What about your privacy?

There are some things about confidentiality that I want to tell you about:

- **I will not use your real name in the research report.**

- **It is okay if you don't want to take part or if you do not want to answer a question.**
- **I will take notes and record what you say but these will be kept very safely.**

If you want to ask any questions please do so.

**If you want to contact me, please call:
XXXXXX.**

My contact address is: XXXXXXXXXX

Consent Form For:

.....

Title of research project: ‘An investigation into why some people with learning difficulties who have part time supported employment in mainstream settings continue to use segregated employment training facilities’.

**Name and contact details of the researcher: Mrs. Wendy Tiplady,
XXXXXXXXXX**

**To be read out by the interviewer
before the beginning of the interview.**

- **The research project has been explained to me and I have been given the opportunity to ask questions about the research project.**
- **I know I can stop the interview at any time.**
- **I know I do not have to answer all the questions if I don't want to.**
- **I know I can change my mind and say 'no' whenever I want.**
- **I know that it is okay to say 'no'.**
- **I know that the interview will be recorded and the information I give will be typed up by either Wendy Tiplady or Janet McCurdy only.**

- **I know that the answers I give to your questions will be kept private and confidential and my real name will not be used in the report about the research project.**
- **I know that I will have the chance to either read or have my answers read back to me when they have been typed up and that I can change anything if I do not agree with what has been written down.**

Yes, I want to take part in the research project:

Signed.....

Date.....

I will have a copy of this form and Wendy Tiplady will keep a copy of the form when I have signed it to say I have understood and agreed to be interviewed and take part in this research project.

Appendix 3

Information Sheet

My name is Wendy Tiplady and I would like your assistance with a research project I am working on for a Masters Degree in Disability Studies with Leeds University.

The research has two aims. The first is to explore the reasons why some people with learning difficulties continue to use segregated work related day service facilities when they have successfully accessed part time supported employment in mainstream settings. The second is to produce and disseminate the findings in a variety of accessible formats, to people with learning difficulties, parents, carers, professionals and senior managers within the Health and Social Services Department.

I would very much appreciate if you would agree to be interviewed for this research project. I would like to ask you about your ideas on why people with learning difficulties continue to come to XXXXXXXXXX Services when they have part time employment. I will do this by conducting focus group interviews. Interviews will be recorded on a digital recorder and will then be transcribed. Interviewees will have the opportunity to see the transcript of their own interview but apart from that, only the researcher and an administrative assistant who will assist in transcribing the data will have access to the recorded data and transcripts.

When the research report is written up, pseudonyms for persons and places will be used as necessary to protect participants' privacy. Furthermore, all information gathered is confidential.

If you agree to participate, please read the attached Consent Form that you will be asked to complete before commencing the interview. Please note also that if you do agree to participate you have the right to withdraw at any time.

If you want to contact me, please call: XXXXXX.

My contact address is: XXXXXXXXX

Consent Form For:

.....

Title of research project: ‘An investigation into why some people with learning difficulties who have part time supported employment in mainstream settings continue to use segregated employment training facilities’.

Name and contact details of the researcher: Mrs. Wendy Tiplady, XXXXXXXXXXXX

- **The research project has been explained to me and I have read and understood the information sheet. I have been given the opportunity to ask questions about the research project and received satisfactory answers.**
- **I understand that I have the right to withdraw my participation in the research at any time.**
- **I understand that I do not have to answer all the questions if I don’t want to.**
- **I understand that the interview will be recorded and the information I give will be typed up by either Wendy Tiplady or Janet McCurdy only.**
- **I understand that the answers I give to your questions will be kept private and confidential**

and my real name will not be used in the report about the research project.

- **I understand that I will have the chance to read the transcripts of my interview and that I can change anything if I do not agree with what has been written down.**

I agree to take part in the above research project:

Signed.....

Date.....

When complete, one copy for the research participant and one copy for the researcher, Wendy Tiplady.

Appendix 4

SEMI - STRUCTURED QUESTIONS: INDIVIDUAL

The following are potential questions only to act as a guideline.
Not to be strictly followed.

Biographical details

- How old are you?
- Where do you live?
- Who do you live with?

Day time activities: work

- Do you work?
- Where do you work?
- How many days a week do you work?
- Do you want to work more hours than you do?
- What do you do at work?
- Do you like your job?
- What do you do during the day when you are not at work?

XXXXXXXXXX Services

- Do you or have you used XXXXXXXXXXXX Services?
- How did you find out about XXXXXXXXXXXX Services?
- When did you start using XXXXXXXXXXXX Services?
- What information did you have about XXXXXXXXXXXX Services before you went there?
- What do you think XXXXXXXXXXXX Services is for?
- (AS APPROPRIATE) What do you/did you like about going to XXXXXXXXXXXX Services?

For those people in work who use XXXXXXXXXXXX services:

- Although you have a job why do you still come to XXXXXXXXXXXX services?

For those in work who no longer come to XXXXXXXXXXXX services:

- Why did you stop coming to XXXXXXXXXXXX Services?

Leisure and Social Life

- Can you tell me what you do each day in the week when you are not at work or XXXXXXXXXXXX Services?
- What do you do at the weekend/ evenings?

- How often do you go out?
- Where do you go other than work or XXXXXXXXXX Services?
- Who do you go out with?
- Do you see people from XXXXXXXXXX Services outside of there?
- Do you meet with the people you work with outside of work?
- Where do you go when you go out?
- Has anyone ever talked to you about doing other things when you are not working?
- Do you need help to do things on the days you are not employed?
- Would you need help, to do other things when you are not working?
- What kind of help do you think you might need?

Life Plans

- Do you know what a Life Plan is?
- Have you ever had a Life Plan?

- If you have, when did you last have one?
- Who was involved in your Life Plan?
- What sorts of things are talked about during your Life Plan?
- Did you talk about other things you could do when you are not at work doing your part time job?
- If you had the opportunity to have a Life Plan, would you like one?

Appendix 5

SEMI - STRUCTURED QUESTIONS: FOCUS GROUPS

The following are potential questions only to act as a guideline.
Not to be strictly followed.

Day time activities: work

Your son/ daughter or the person you support is employed part time-

- Do you think X likes their job?
- Do you think X wants to be employed for more hours than they are at the moment?
- What does X do during the day when they are not at work?

XXXXXXXXXX Services

- Your son/ daughter or the person you support has used or still uses XXXXXXXXXXXX Services -
- How did you find out about XXXXXXXXXXXX Services?
- What information did you have about XXXXXXXXXXXX Services, before X went there?
- What do you think XXXXXXXXXXXX Services is for? Why do they or did they come to XXXXXXXXXXXX Services?
- (AS APPROPRIATE) What do you think X likes or liked about coming to XXXXXXXXXXXX Services?

For those people in work who still use XXXXXXXXXX services:

- Although X has a job why do they still come to XXXXXXXXXX Services?

For those in work who no longer come to interwork services:

- Why did X stop coming to XXXXXXXXXX Services?

Leisure and Social Life

- Can you tell me what X does each day in the week when they are not at work or XXXXXXXXXX Services?
- What does X do at the weekend/ evenings?
- How often does X go out?
- Where does X go other than work or XXXXXXXXXX Services?
- Who does X go out with?
- Does X see people from XXXXXXXXXX Services outside of there?
- Does X meet with the people they work with outside of work?
- Has anyone ever talked to you about X doing other things when they are not working?

- Does X (or you) need help to do things on the days they are not employed?
- Would X need help, to do other things when they are not working?
- What kind of help do you think X or you might need?

Life Plans

- Do you know what a Life Plan is?
- Has X ever had a Life Plan?
- When did X last have one?
- Who was involved in their Life Plan?
- What sorts of things are talked about during the Life Plan process?
- Did they or you talk about other things that X could do when they are not at work doing their part time job?
- If X had the opportunity to have a Life Plan, do you think they would like one?

Appendix 6

Criteria for the Learning Disability Registration

- (i) Individuals are aged 18 years or over.
- (ii) Learning disability is defined as referring to:
 - i. a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
 - ii. a reduced ability to cope independently (impaired social functioning);
 - iii. which started before adulthood, with a lasting effect on development.

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as people with Asperger’s Syndrome.

(The above two points refer to DOH (2001) Valuing People: A new strategy for Learning Disability for the 21st Century – A White Paper)

To clarify the definition further, it may be helpful to consider those people who would not be included in this definition:

- i. people who develop an intellectual disability after the age of 18
- ii. people who suffer brain injury in accidents after the age of 18
- iii. people with complex medical conditions which affect their intellectual abilities and which develop after the age of 18 - for example Huntington’s Chorea, Alzheimer’s Disease
- iv. people with some specific learning difficulties eg. Dyslexia, Attention Deficit Hyperactivity Disorder.

Appendix 7**Table 1** Demographic Information of Community Day Services use

People	Workshop base	Day Centre for adults with a learning difficulty	Day Centre for adults with physical Impairments	College	Home	Part time employment
4	✓	✓				
5	✓	✓			✓	
3	✓			✓		
9	✓				✓	
2	✓			✓ 2 days		✓
6	✓					✓
2	✓ 5 days					
2	✓		✓		✓	
1	✓	✓		✓2days		
1		✓				✓ receives attendance allowance from w/shop for post delivery
1	✓	✓				✓
36						

Appendix 8**Table2** Demographic Information of informants: M = male, F= female

Gender	Age	Type of employment	Hours worked per week	On how many different days are the hours worked	Domicile
Group 1					
M1	40	Bank - post delivery	15	5	Group home
M2	45	1)Factory 2)Hospital – incinerator operative	15 4.5 =19.5	3	With parents
F1	18	Fulfillment	12	3	With parents
Group 2					
M3	51	1)Bank - post delivery 2) Hospital- incinerator operative 3) Stationary delivery	6 9 2 = 17	5	Supported living-own bed sit
M4	56	Supermarket	20	5	Supported living-own bed sit
F2	24	Office	20	4	With parents

Appendix 9

Table 3a: The codes that constitute the super-code “*Organisational aspects*” with definitions and examples.

Super-code	Sub-code	Definition	Example
Organisational aspects	The role of the WB -		
	Seen as work	Seen as work	“I see it as a place to work, a change of work, do more work”. “It gives people a bit of work to do”. “It was a place to come and work”. “For people to do work”.
	Work experience	Work experience in various work settings	“To do work experience”. “Found out about it at school”. “It helps you to try different jobs”.
	Stepping stone	Supported to learn about work, trying different jobs	“It gives you a taste of what work is like”. “I came when I was at school and college; it helped me to get to know about work and to get to know everyone”.
	Place to meet friends	Place to meet friends	“It gives a chance to meet up with and keep in touch with friends”. “I like chatting with all my friends”.
	To help find a job	Support to help find contracted employment	“To talk about work”. “To help find a job”. “A place to help get some work”. “To get a job”. “For talking- talking about work”.
	Somewhere to go	Somewhere to go, something to do	“It’s somewhere to go”. “To give people something to do with their day”. “I’d get bored at home”.

Table 3b: The codes that constitute the super-code "*Organisational aspects*" with definitions and examples.

Super-code	Sub-code	Definition	Example
Organisational aspects	Length of time appropriate to stay at WB	When part time employment found, length of time appropriate to stay at WB not clear	<p>"People should stay as long as they want to really".</p> <p>"I only wanted to stay until I got a job- the WB wasn't for me- but was good for staff to get to know me and me to get to know them".</p> <p>"If there's an opportunity to do some outside work, go for it".</p>
	Attendance allowance	Organisation pays attendance allowance	<p>"It's not a wage it's just like a bit of pocket money".</p> <p>"Other people said a wage and no, when somebody asked me that question I said attendance money. The majority of us when we had discussions said attendance money".</p>

Appendix 10

Table 4a: The codes that constitute the super-code '*Social aspects*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Social aspects	General social activities:	Activities in social or non work time	
	With work colleagues	Social activities / relationships with work colleagues	<p>"I see them as friends at work, not out of work".</p> <p>"The department is organising a meal sometime and I will go on that".</p> <p>"No, don't go out with work colleagues, not out of work".</p>
	With friends	Social activities / relationships with friends	<p>"I go out with friends sometimes not very often".</p> <p>"Most Fridays I go and see a friend- we have known each other since we were three; we went to the same school".</p> <p>"I go and play bingo with one or two friends on a Saturday night".</p>
	With family	Social activities / relationships with family	<p>"I go and see Mum".</p> <p>"Monday, Wednesday, Saturday I see Dad".</p>
	In the evenings/weekends	Social activities / relationships in the evenings / weekends	<p>"I stay at home most of the time".</p> <p>"I go to meals out, the theatre, leisure centre, swimming". "I watch the telly". "I meet friends from college at club".</p>

Table 4b: The codes that constitute the super-code '*Social aspects*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Social aspects	Community activities	Activities in local community-	
		Exercise	"Tuesday afternoon we go to physio-fit". "I would like to go to the gym." "Thursday, I go swimming".
		Town- shopping	"Do shopping on my own". "I go to town".
		Service related	"I go to club every Tuesday". "I socialise at club Tuesday and Friday".
	Routine activities	Regular predictable activities e.g. Every week	
		Tidy room	"I tidy my room when not at work".
		Washing	"I do the washing every Friday".
		Gardening	"I like gardening".
		Television	"I watch the telly". "On a quiet day, I watch the telly".
		Visit my Mum	"I visit my Mum every week".

Appendix 11

Table 5a: The codes that constitute the super-code '*Reasons for staying/not staying at the WB*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for staying at the WB	Discussion or information about alternatives	Whether alternatives to staying at the WB when part time employment taken up was discussed	"Not really".
	Something to do	Something to do	"I would get bored if I didn't come". "It's to give them something to do with their day".
	Attendance allowance	Attendance allowance seen as important	It's not really a wage; it's just like a bit of pocket money". "I enjoy getting my pocket money attendance".
	Place to meet friends	Place to meet friends	"I like to meet up with my friends".
	No perceived time limit	Length of time people can stay at the WB	"I think people should stay as long as they want to really". "I think people should come for as long as they want".
	Seen as work- Enjoys the "work"	Seen as work	"It's a place for people to do work". "I enjoy the work and it's what I can cope with".
	Had attended WB on full time basis / or more days than part time employment	Continued attending on the days when not employed	"I just carried on coming". "When I got my job, I carried on coming on the days I wasn't working in my job". I carried on coming at first but then I decided to not come any more. I wouldn't want to come back now".

Table 5b: The codes that constitute the super-code '*Reasons for staying/not staying at the WB*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for staying at the WB	Seen as a "stepping stone"	Supported to learn about work, trying different jobs	"It has helped me to understand about work but still see my friends. I don't think I will want to stay. Not sure if I am ready to leave yet or if I want to work more hours".
	Seen as a waiting place		"A place to wait and get some help to get more work".
	Life Plan	Not had one or not discussed other things to do when not working	"I have had one but a long time ago when I went to the centre". "I have not heard of Life Plans".
	Preferable to "day centre"		"I would rather come here and do work rather than the centre".
	Support to do other things		"I could do other things if I had some help". "I'd like to be able to go to a gym- if I could get help just for a month, to build it up, then I could perhaps carry on". "If my Mum didn't give me a lift I would need help getting to places".

Table 5c: The codes that constitute the super-code “Reasons for staying/not staying at the WB” with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for not staying at the WB	Found a job	Found employment	“I got a job and I like getting paid”. “I really like my job and I don’t want to come back”.
	Stepping stone	Supported to learn about work, trying different jobs	“I stayed in the mornings when I first got my job in the afternoons but now I like to stay at home and do other things. I like going to town on my own”.
	Enjoyed doing other things		“I stopped coming because I could”. “I enjoyed staying at home and watching the telly or going for a walk, I could do that when I moved to Supported Living”.
	Support to do other things	Support given to do other things	“Supported Living helped me to do other things, so I stopped coming”. “They help me if I need them to”. “I meet my friend and my befriender. My Mum gives me a lift because the buses are a bit difficult”. “I get a lift with Mum because the buses not good, may need support with transport”.
	Supported living	Independent living with varying levels of support	“My dad normally takes me, so I need a lift unless the place I was going was closer”. “I can stay at home or do whatever I want”. “I like to do gardening at home”.

Table 5d: The codes that constitute the super-code “Reasons for staying/not staying at the WB” with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for not staying at the WB	Attended the WB on a part time basis	Had only attended the WB on a part time basis	“I only came part time so when I got my job I left”.
	No intention of staying	Had not ever thought about staying	“I didn’t want to stay; I just wanted help to get a job”. “I don’t want to work any more hours than I am doing and my Mum helps me to do things when I am not working”.
	Life Plan	Person centered planning	“I have had a life plan but I can’t remember when I last had one and I don’t remember talking about doing other things when not working”. “I talked about a lot of things”.
	Discussion or information about alternatives	Whether alternatives to staying at the WB when part time employment taken up was discussed	“Not really but I stopped because I wanted to do other things”. “I don’t remember talking about it, I didn’t stop coming straight away but I decided I didn’t want to come anymore after a while”.

Appendix 12

Table 6a: The codes that constitute the super-code '*Organisational aspects*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Organisational aspects	The role of the WB –		
	Seen as work	Seen as work	“To try things out through work experience”. “To provide support”.
	Work experience	Work experience in various work settings	“As a stepping stone; maybe they should come as long as they want”.
	Stepping stone	Supported to learn about work, trying different jobs	“Before it was mainly a workshop, if you like, and you worked in the workshop whereas now you’re looking at getting the people out to work, so it’s just a stepping stone if you like”.
	Place to meet friends	Place to meet friends	“They come for the social part and they don’t have alternatives”.
	To help find a job	Support to help find contracted employment	“To help people to find work”. “To have them there to give them something to do in the meantime”. “To find out how they can cope”.
	Somewhere to go	Somewhere to go, something to do	“One person does the part time jobs that he’s got and then comes to the workshop to “fill in the time”.

Table 6b: The codes that constitute the super-code '*Organisational aspects*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Organisational aspects	Length of time appropriate to stay at WB	When part time employment found, length of time appropriate to stay at WB not clear	"I don't think they realised they could stop going".
	Attendance allowance	Organisation pays attendance allowance	"He likes getting his attendance allowance as well as his wages".

Appendix 13Table 7a: The codes that constitute the super-code '*Social aspects*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Social aspects	General social activities-		
	With work colleagues	Relationships / activities with work colleagues	"It does help expand contacts and build relationships but not necessarily friendships". "They would go on a staff night out".
	With friends	Relationships / activities with friends	"She goes out with friends from college who are her own age".
	With family	Relationships / activities with family	"It's what we think of the two us together"
	In the evenings	Activities in the evenings / weekends	"He does a lot of things; Adult evening class but he has been going for twenty years! Advocacy group, bowls, club and sometimes meets mates from school at bingo".

Table 7b: The codes that constitute the super-code *Social aspects* with definitions and examples.

Super-code	Sub-code	Definition	Example
Social aspects	General social activities		“But why couldn’t they do the same as anybody else who only works part time? Go for a walk, do some gardening, visit friends”.
	Routine activities	Regular activities e.g. Every week	“A lot of people tend to go to places that are organised – Club, Night School”. “Saturday morning bowling has enabled people to go off island and compete in competitions”.
		Tidy room/Washing	“They tidy their room and do their washing on their days off”.
		Gardening	“He takes great pride in his plants and seeds”.
		Visit Parents	“He’s always at his Dad’s”.
		Exercise	“They do the same as everybody else-who works part time really; go for walks, library, shopping”.
	Community activities	Town - shopping	“He goes to Town on his own”.
		Service related	“They go to Clubs and night school”.

Appendix 14

Table 8a: The codes that constitute the super-code '*Reasons for staying/not staying at the WB*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for staying at the WB	Discussion or information about alternatives	Whether alternatives to staying at the WB when part time employment taken up was discussed	"I don't think it was really talked about and I don't think they realised that they had the choice at first".
	Something to do	Something to do	"He goes because he can". "It became a habit, attended the centre and carried on".
	Place to meet friends	Place to meet friends	"I know a lot of them also, for lots of reasons, still want to have contact with the workshop, possibly from the social set up – meeting up with people that they went to school with years ago, meeting new people, having a laugh and I think there's an element of that".
	No perceived time limit	Length of time people can stay at the WB	"He became institutionalised, still in segregated services, must stop it happening for younger people".
	Seen as work - Enjoys the 'work'	Seen as work	"He carried on coming because he enjoyed it". "He thinks of it as work and may feel that he was being 'sacked' if he couldn't go anymore".

Table 8b: The codes that constitute the super-code '*Reasons for staying/not staying at the WB*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for staying at the WB	Had attended WB on full time basis / or more days than part time employment	Continued attending on the days when not employed	"She started off with being supported by staff, which was perfect for her".
	Seen as a 'stepping stone'	Supported to learn about work, trying different jobs	"We want her to be as independent as possible and working is part of that. It's been an incredible placement for her". "It's worked beautifully to build up her confidence until she is ready to get more hours".
	Life Plan	Not had one or not discussed other things to do when not working	"She has never had the opportunity to have one and I wouldn't know who to turn to if there was a problem. I don't know which department to contact. It should be available".
	Preferable to 'day centre'		"He decided not to go to the day centre any more as he preferred the WB".
	Support to do other things		"There should be more staff support for people to do other things when they're not at the WB".

Table 8c: The codes that constitute the super-code '*Reasons for staying/not staying at the WB*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for not staying at the WB	Found a job	Gained employment	"Then the job came. Worked out fine. She wouldn't think to come back now".
	Stepping stone	Supported to learn about work, trying different jobs	"Work experience has helped her to gain confidence and move into employment".
	Attended the WB on a part time basis	Had only attended the WB on a part time basis	"She only came part time and then she got the job on the days she used to come".
	Enjoyed doing other things		"They enjoy doing the same things as other people who work part time".
	Supported to do other things	Support given to do other things	"Supported Living has been great for them; they have a lot more confidence. It's been brilliant the way they have changed. We used to cook for them, look after their monies, their needs. Now the staff does literally what it says; we support them, we give them the choice. We encourage them to live an ordinary life".
	No intention of staying	Had not ever thought about staying	"I don't think she ever wanted to stay and her days were filled with other things".

Table 8d: The codes that constitute the super-code '*Reasons for staying/not staying at the WB*' with definitions and examples.

Super-code	Sub-code	Definition	Example
Reasons for not staying at the WB	Life Plan	Person centered planning	"Some of them don't want to have Life Plans anymore but in supported living we try and talk about things as they happen".
	Discussion or information about alternatives	Whether alternatives to staying at the WB when part time employment taken up was discussed	"We did talk to them about it but not until they were in their part time jobs and we told them they don't have to go to the WB if they don't want to".
	Support to do other things		"I give her lifts when she needs them or she catches the bus. We do a lot of things together; go to the theatre, shopping, physio fit".
	Supported living	Independent living with varying levels of support	"We support them but we try and give them their independence and we give them the choice, that's the big word, choice".