# THE BARRIERS TO WORKING LIVES: THE EXPERIENCES OF DISABLED PEOPLE

**Frances Chapman-King**

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**Department of Social Policy and Social Work**

**University of York**

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## Abstract

Economic exclusion of disabled people (DP) is not a new phenomenon, with a history dating back to the industrial revolution, and forward with increasing prevalence in what has been characterised as the information age.

In common with other Western Capitalist Societies the incidence of facture from the labour market [of disabled people] is increasingly common in the UK, with more than 2.7 million DP of working age out of work. This increase in numbers in receipt of Incapacity and other disability benefits has become a key political issue with concerns expressed for the cost to the taxpayer, alongside the issue of [DP as] a potential labour supply in what is termed as a tight labour market. The focus of policy initiatives has been to engage with those recently in receipt of Incapacity Benefits, many of whom do not identify with disability, with ill health and disability used interchangeably in policy documents. This confusion of terms serves to risk policy failure and may also serve to create a hierarchy of disability, with those deemed the most able sick or disabled being castigated as the undeserving poor.

A plethora of social policy, whose stated aim is to support and help DP into work, has made no significant dent in the statistics, and evaluation of government programmes serve to measure the outcomes of the policy, without consideration of the underlying cause of the [economic] exclusion.

There is a dearth of literature recounting the perceptions and experiences of disabled people and work and in particular from a social model perspective. What are the views of disabled people themselves? How do they see this increasingly political agenda of work and workfare? What are their aspirations and experiences of a social structure [paid work], that is seen as a measure of full citizenship?

This research project sought to give a voice to disabled people’s aspirations to, and experiences of work, and recount how DP view the contribution they make to a society structured around the paid job role. In doing so the barriers to work experienced by DP are explored, with some analysis of the strategies used to gain and stay in work.

The research method used was qualitative, reflecting the aim to capture individual in depth accounts of personal experiences, and this was achieved through 12 semi structured interviews.

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And finally, I would like to dedicate this work to the memory of two people who have enriched my life beyond measure, and without whom the world is diminished.

To my mother Irene, to whom I owe it all.

For Muriel, my true and great friend.

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## ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| AtW | Access to Work |
| DDA | Disability Discrimination Act |
| DEA | Disability Employment Adviser |
| DRC | Disability Rights Commission |
| DWP | Department for Work and Pensions |
| IB | Incapacity Benefits |
| JSA | Jobseekers Allowance |
| ND | New Deal |
| NDDP | New Deal for Disabled People |
| NHS | National Health Service |
| ODI | Office for Disability Issues |
| OECD | Organisation for Economic Co-operation and Development |
| PMSU | Prime Ministers Strategy Unit |
| PTWP | Pathways to Work Pilots |
| RA | Reasonable adjustment |
| SENDA | Special Education Needs and Disability Act |
| WHO | World Health Organisation |

# Chapter 1 Introduction

Despite a proliferation of social policy aimed at increasing the economic participation of disabled people [see Appendix 1], underpinned by the DDA(1995)[1] giving the first rights in employment, the employment rate of disabled people in the UK remains stubbornly low with an unemployment rate of 52.6% (DWP, 2006.45), the lowest employed group. Labour Force survey details tell us that this picture is in the face of record high employment levels [of 75%] of those of working age, with the disparity between the two meaning that Disabled people are three times as likely to be economically inactive (Disability Rights Commission, 2006). The economic back drop of increasing prosperity in the UK masks the polarisation of high skilled high paid work and low skilled low paid work, the latter being where disabled people who are employed are disproportionately concentrated. Unemployment and poverty[2] are two sides of the same coin with a significant correlation between labour market exclusion and poverty (Palmer et al, 2006). This poverty exacerbates the economic exclusion endured by disabled people to a wider social exclusion[3] from participation in society in general. Disabled people are disproportionately at risk of poverty, and also to have higher outgoings related to their disability (Smith et al, 2004). This poverty is enduring and well documented by Walker and Townsend (1981) for example, and more recently by Burchardt (2000, 2004) and Palmer et al (2006).

In common with other OECD countries, rates of recipients of Incapacity Benefits (IB) in the UK has risen considerably since the 1980's now standing at over 2.7 million (DWP, 2006.11). This almost trebling of numbers in receipt of IB, has occurred during a period that witnessed dramatic restructuring of the labour markets of western capitalist societies and the rise of the global economy, with redundant workers encouraged onto IB, for the political advantage of reducing unemployment figures (Warren, 2005.307).

That the employment rate of disabled people has remained persistently low [in a prosperous economy] is of concern for policy makers and government, and the ‘culture of dependency’ created by the welfare state is seen as part of the problem. Dean and Taylor-Gooby (1992), Thornton and Lunt (1997) and more recently Roulstone (2004), find that the evidence of high poverty amongst DP does not reflect the dependency culture view, and the disincentives to work may be taken to be the barriers to work such as low pay and discrimination.

This governments response is to reform the welfare state, and the welfare reform Green Paper (1998) was launched with the stated policy aim of ‘Work for those who can, and security for those who cannot’, firmly establishing the New Labour paradigm of equality, as that of equality of opportunity [to work]. The flagship programme of the Welfare to Work agenda is the New Deals[4], initially focused on youth unemployed, which has shown moderate success. New Deal for Disabled People (NDDP)[5] came on line later and with considerable less funding and success (Dickens et al 2003.30), reflecting in part the lack of reliable information about people with disabilities and long term illnesses, and how to get them into paid work (Stafford, 2003). There remains the unanswered question of where the jobs will come from in areas of high unemployment, and little of significance disclosed as to ‘security for those who cannot’, in terms of [increase in] benefit levels (Palmer et al, 2006).

Latterly the formation of Jobcentre Plus (JCP) [on a rolling programme from 2001 to 2006], which joins up employment and benefit services and delivers to all those of working age, and the Pathways to Work Pilots(PTWP)[6], delivered in partnership with the NHS, provide a more intensive approach to helping IB recipients back into work. The focus is on new IB claimants [who are closer to the labour market] as an emphasis on outcomes encourages selection of the most ready or able, and in so doing allocates resources arguably in inverse proportion of need (Thornton and Lunt 1997). More recently Stafford (2007) finds that this selection has extended to Job brokers, delivering (NDDP) programmes on behalf of JCP, who employ ‘strategies’ to ensure less ready applicants do not register.

Policy interventions are primarily focused on supply side[7] measures, for example NDDP, and a medical model[8] of disability, encompassing both sick and disabled people. The variations of definitions of disability[8] and the rules for receiving IB, requiring claimants to prove their *incapacity* to work, may serve to contribute to policy confusion in a policy area seen to be increasingly politically important. Views in the literature on the reasons for this increased focus, range from [a Marxist view of] a tight labour market with disabled people being seen as a reserve army of labour [keeping inflation and wages down] (Grover and Piggott (2005.715)), to disabled peoples rightful expectation to be a part of what has been characterised as an opportunity society.

The Prime Ministers Strategy Unit (2005) joint report set out the governments vision for disabled people to be fully within the scope of the opportunity society by 2025, by supporting disabled people to help themselves. This ambitious four strand agenda includes ‘Improving support and incentives for getting and staying in employment’ (PMSU 2005.8). The strategic vision adopts, [for the first time], a social model[8] barriers approach to inclusion, reflecting the influence of the disability movement[9] in advancing the social model of disability, and placing civil rights for disabled people on the political agenda. The setting up of the Office for Disability Issues (ODI)[10] [in 2005] and a new advisory body, Equality 2025[11] [in 2006], marks the next phase in this governments stated commitment to involve disabled people at the centre of decision making (ODI. 2006).

In summary the current policy initiatives aimed at both sick and disabled people [as one homogenous group] with a language of inclusion and mainstream, runs parallel to the disability movements agenda for full civil rights, and for equal access to what could be termed good jobs. There is a tension here as sick and disabled people are not necessarily the same and, for example, a disabled lone parent *may* have more in common with an able bodied lone parent in terms of policy intervention, than someone who has a broken leg that will mend in time. Further, the governments work first approach [to combat exclusion], or simple supply sideism of NDDP and PTWP, does not match the agenda for full civil rights, and for access to good jobs. There is a danger that this tension may serve to formulate an agenda that is talking across one other.

It is from this perspective that this study is grounded in the views and experiences of disabled people themselves, underpinned by the social model concept of the barriers to participation [of disabled people] in the world of work.

My interest in this policy area has been fostered over a lifetime by my personal experience of periods of segregated education; of working as a disabled person; by my work in JCP, and as Chairman of the Board of Trustees of Newlink[12] – a training and trading organisation of disabled people. I chose to research this area as I have experienced many strands of this [developing] policy agenda, and my aim is to increase the small body of work written from the perspective of the most important stakeholder in this current hot topic of social policy, disabled people themselves. Barnes et al (1998) identified a lack of account of how disabled people experience employment, and Roulstone (2003) highlights the lack of research exploring the experiences of disabled people at work, from a conceptual framework of the social model of disability. Roulstone further highlights that how DP and policy interact at the micro level, may be the only real way to measure effectiveness [of policy delivery]. By capturing the personal and unique stories of the experiences of working with a disability, it is intended that the findings from this research may contribute to the theory and practice of social policy.

Chapter 2 will outline the background and context of economic exclusion of disabled people in the UK, and the current agenda of welfare to work. In so doing some analysis of the changing structure of the UK labour market will be made.

Chapter 3 will review the relevant literature of the experiences of disabled people in work, including the barriers enablers and strategies used for gaining and staying in work.  Whilst not seeking to evaluate the effectiveness of NDDP or PTWP, other than to illustrate a point, relevant literature, including that which evaluates programmes aimed at DP and IB recipients, will be drawn upon where it identifies the barriers to or experiences of work.

Chapter 4 will detail the research methods used, and will outline the reasons for choosing a qualitative study for this topic.  It will show how the study was planned and carried out, and how the data obtained was analysed.  In the genre of emancipatory research, this study was conducted within a conceptual framework of the social model of disability, with the voices of disabled people at the centre.

Chapter 5 will present the results and data gleaned from the interviews, by using descriptive and explanatory accounts of the findings.  An analysis of links and patterns found within the data will be mapped back to the research questions.

Chapter 6 will draw conclusions from the data captured in this study, and in particular in relation to the key areas identified in the literature review.  And finally the implications for social policy will be explored within the context of the research.

## Chapter 2 – Context and Background

### 2.1

In political terms disability and work has a high profile in part reflecting concerns about the growing numbers of people of working age in receipt of IB, and also through the political activation of disabled people by the disability movement. The profile of people who claim IB shows that once in receipt of this benefit the duration of the claim is usually long term, with the average length of claim 8 years for those in receipt of IB for more than 12 months (DWP, 2002.6). Of the 2.7 million people in receipt of IB, one third say that they want to work (DWP, 2002, DWP, 2005).

### 2.2 What has caused this seeming rise in ill health and disability, and how do we define who can and cannot work?

There has been some increase in the number of people who declare a long standing disability or health problem from 15 to 19 per cent (DWP, 2002.7). Other factors at play include structural changes in the labour market (LM) (Castells, 2000), the effects of globalisation[13] and the rise of the third world economies. The UK, once the engine house of manufacturing industries, now has a primarily service sector LM. [Other demographic factors are at work, such as an increased ageing population with consequential age related ill health or disability, and an increase in women's economic activity with the rise of the flexible and primarily service sector labour market. These factors are acknowledged, however are not specifically explored in the text.]

The flexible service sector jobs market is a double edged sword of opportunity, with an emphasis on personal skills, teamwork and adaptability, facilitating womens participation at the expense of traditional male job roles (Thornton and

Lunt 1997). It also serves to reduce opportunities for others, in particular people with a learning disability (Barnes 1991), (Goodley and Norouzi, 2005).

The UK labour market has polarised to high skill high paid work, and low paid low skilled work, in what has been characterised as an information society (Nickell, 2002). At the macro level the UK has stable low inflation, the lowest unemployment rate for 30 years, and increasing prosperity. This polarisation [of work and income] has resulted in high rates of poverty and social exclusion. (Gordon, 2002), (Palmer et al, 2006).

## 2.3 Welfare to Work

The work first approach underpins the wider commitment to eradicate child poverty by 2020, and work is seen, as the best route out of poverty and exclusion for all disadvantaged groups, having echoes of the undeserving poor. More recently The Welfare Reform Bill (2007) shows increased conditionally for those termed sick or disabled, with mandatory work focused interviews [as in PTWP], and a new two tier benefit, reflecting the path dependency of less eligibility. Pathways to Work [PTW] is to be rolled out as a national programme by April 2008, with a mixed delivery of provision as is currently. The methods employed [in New Deal and PTW] are supply side policies, reflecting the neo classical liberalism of the polity, with an emphasis on the free market [non intervention and persuasion, rather than compulsion], with conditional welfare.

NDDP uses a ‘work first’ rather than a ‘human capital investment’ approach and is currently about matching DP existing skills with those of prospective employers. This simplistic supply side approach fails to recognise the significant barriers of low skills [with consequential low paid work options], underemployment and in sum labour market discrimination that disadvantage and disable those with an impairment (Palmer, 2006.26). The PTW main programme *is* NDDP, with an add on of the condition management programme designed to facilitate better management of health and disability issues, emphasising the medical model concept underpinning the supply-side approach. For example the (2007) Welfare Reform Bill allows for regulations to be taken to make priorities for *requiring* customers to take part in health related assessment, including assessments on rehabilitation.

## 2.4 The link to poverty

The risk of child poverty is significantly increased by having a disabled parent, as disabled parents are less likely to be in work. It has been shown however the move to work does not decrease this risk, as the employment opportunities open to DP mean the work is likely to be flexible and low paid leading to in-work poverty (Strickland and Olsen, 2006.43), (Palmer et al 2006.11). Poverty rates among disabled adults of working age is now higher than for either children or pensioners; is twice than of non-disabled adults; and has increased in the last decade (Palmer, 2006.22). What these statistics show is that poverty is a disability issue, as acknowledged by the minister for disabled people (Disability Now, January 2007).

## 2.5 Is disability and ill health the same thing, or does this mix of terminology risk policy confusion?

The path dependency of deserving and undeserving poor is implicit in the Welfare State from the Poor Laws through to the present day, (Finklestein, 1996) (Borsay, 2005). The rejection of Keynesian[14] economic ideas in the early 1980s, was mirrored by the rise in the politicisation of disabled people through the disability movement, with a full civil rights agenda.

The disability movement argued for their civil rights to full inclusion[15] in society, rather than [inadequate] benefits to compensate for exclusion. By turning on its head the orthodox view of the individual or medical model of disability where the ‘deficit’ is located in the individual disabled person, and thereby the social obligation [to work] is excused [by the sick role] in a paternalistic welfare state, the social model viewed the debate from the barriers constructed by the institutions and society which are based on an abled bodied ‘norm’, (Barnes et al, 1999).

This able bodied norm has served to exclude disabled people from work from the period of the industrial revolution, with the consequential commodification of labour. Disabled people [who could not conform to this ‘normal’ regime and the speed or dexterity of factory work] were excluded from employment [and a society structured around the job role], into segregated low status work, or through unemployment [into] the workhouse (Borsay, 2005). This exclusion remains to the present day and has been aggravated by the rise of the information society with a premium placed on skills, and the effects of globalisation (Castells, 2000).

In sum, the effects in the UK labour market have been a dramatic reduction in manufacturing and the availability of low skilled jobs with a corresponding rise in service industry, casual, and flexible jobs, and high skilled technical work (Dickens et al 2003). The impact on disabled people and work opportunities is magnified as disabled people are disproportionately low skilled, being twice as likely to have no skills and half as likely to be qualified to degree level as non disabled people (DRC, 2006). Even when high skilled and qualified to degree level, for example, DP are more likely to be unemployed than an unqualified non disabled worker (Palmer et al, 2006.17). Further ‘at every level of qualification, the proportion of people with a work-limiting disability who want but lack work is at least three times the rate for similarly qualified people without a disability’ (Palmer et al, 2006.24).

Disability therefore is a socially constructed, and increasingly politically defined, term. The models of disability are discussed more fully later in this chapter.

## 2.6 Is the work first approach squaring the triangle of disability, work and poverty?

The neo-liberal workfare regime of the 1980 and 1990s has been characterised as a competition state by Evans and Cerny (2003) with the objective to mobilise all who can into often low paid work in a global economy (see Appendix 2).

New Labour [from 1997] has sought to ameliorate or redirect the neo-liberal approach so that economic and social policies appear to support each other (Evans and Cerny, 2003). The increasing conditionality of welfare is evident in 'as support is increased, so will the conditionality for claimants' (DWP, 2006). DP who are excluded from work and in poverty on welfare, may now be pushed into low skilled low paid work (Preston, 2006.5). Inadequate benefit levels create a poverty trap for DP due to the costs of disability, and low paid work exacerbates that poverty level (Smith et al, 2004), (Roulstone 2000, 2004) (Treolar, 2006). See Appendix 3 for some examples.

The poverty rate for working age adults has remained unchanged in a decade of Welfare to Work, and crucially has increased when living in a working household. For DP the risk is magnified, with working age disabled adults twice as likely to be in poverty as non disabled adults, and shows an increase since 1997. These findings are attributed to; in work poverty; the lack of paid work; and low rates of replacement benefits (Palmer et al 2006.16). The mark of success of social security policy is alleviating poverty, the authors find that for DP, in particular, the work first approach is not working.

In summary, economic inclusion and disability are high profile on the political agenda due to record levels of people of working age in receipt of IB, concern for the cost of welfare, and the politicisation of DP through the disability movement.

The objectives of the government and the disability movement appear at first glance to be aligned.

The tension arises from the right to work being termed as a responsibility to work with the governments view of a dependency culture, whilst the discriminatory attitudes and other barriers that prevail mean the likelihood is that work will be low skilled and low paid, creating a poverty trap (Roulstone 2000, 2004). Whilst neither the distribution [across employment sectors] of disabled people, nor their impairment is well documented due to the lack of consistency in definition of disability or impairment, the varying terms used such as ill health, long term illness, impairment or work limiting disability, for example, are often used to convey different interpretations and findings from the same set of circumstances (Berthoud, 2006).

## 2.7 Models of Disability

The emergence of the social model concept of disability has its roots in the 1960s and 1970s with the work of Hunt (1966) for example, who challenged the value system of a society that segregated and excluded disabled people, with associated social stigma, as less than ‘normal’. Hunt was also instrumental in the setting up of UPIAS (Union of the Physically Impairment Against Segregation) and in 1975 the definition of Impairment and Disability that formed the basis of the social model of disability was born. The definition is repeated here:

> Impairment: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
>
> Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation

> in the mainstream of social activities. Physical impairment then is a form of social oppression. (UPIAS 1975.14 in original document).

The definition was later widened to include sensory and intellectual impairments, and was first applied by Oliver (1983.23). Drawing on the influences of Karl Marx and others, Oliver (1996) views the oppression of disabled people as a social creation of capitalism, and the social model concept of disability is rooted in a theoretical basis of DPs oppression by a society constructed around an able bodied norm. Disability theorists view the issue from the disabling barriers constructed by society that disable those with an impairment. The [opposing] socio-medical [or medical model] view is concerned with defining chronic illness and impairment, centred on the individual or deficit model of disability (Oliver, 1996), (Barnes and Mercer, 2003).

Criticism from within the disabled academy, for example French (1996) Shakespeare (2006), seek to bring impairment back in. Oliver (1996, 2004) defends the social model as ‘not a full social theory’ nor is it intended to be, more a heuristic tool to use to gain an alternative understanding of disability. For him the critical factor is that the social model is an intentional move, or focus away from the personal to the political, to achieve collective ends.

The tensions between the two models centres on; the causal link between impairment and disability; the different social and constructed meanings in the language used; and the differences and commonality between ill health and impairment. This latter point may serve to risk policy failure, as activation programmes aimed at one may be ineffective for the other, [for example poverty and the work first approach].

The tension in the literature considering disabled people and work arises primarily from the inconsistency in the definition of impairment and disability, and in the language used in considering who is ill, disabled or impaired makes comparisons and findings across the available research difficult and at times unreliable.

## 2.8 Motivation

There is no definitive theory of motivation to work. A brief exploration of motivation is undertaken here, as context for the empirical study. The classical school is expounded by Taylorism , where people are seen as cogs in a wheel who need to be measured [output] and incentivised [financially rewarded] to work. Fayol later added penalties for failing to perform, giving rise to the ‘cannot and stick’ method. The basis of Taylor and Fayol’s theories were that man would do as little as possible for the largest reward, and was motivated by his own utility (Vroom and Deci 1992) having echoes of [the eighteenth century economist] Adam Smith.

At the other end of the theoretical continuum, Maslow’s (1943) hierarchy of needs (see Appendix 4) provides the basis for McGregor ‘Theory Y Management’ which espouses that motivation is part of man’s natural desire to work, to perform useful tasks and in essence contribute to society, he is therefore self motivated. Vroom goes further and finds that human nature is motivated by achieving [inspirational] goals and satisfying psychological needs (Vroom in, Vroom and Deci, 1992).

Warr et al (1979) devised a scale to measure work motivation which was linked to job satisfaction – such as personal achievement, and Warr (1982) links unemployment with psychological distress. Barnes (2000) finds that DP held similar views to non-disabled people, with the primary motivation [to work] to be financial, and because work is ‘normal’ or enjoyable. Goldstone and Douglas (2003) cite money and sociability as the reasons to work [for customers in receipt of IB]

In sum, people are motivated to work by their own personal utility, and will only work to enhance it.  This resonates with the supply side policies of welfare to work, underpinned by a neo-liberal polity heavily drawing on Adam Smith philosophy, and shows threads of Hertzberg's (in Vroom and Deci, 1992) POSITIVE KITA in compulsion and sanctions.  Alternatively, people are motivated by a hierarchy of [satisfied] needs, and that it is part of man's natural desire to achieve his or her potential.

Chapter 3 will now consider these issues in more depth, and will review the relevant literature about the barriers to work, in essence the dichotomy of [the governments] dependency culture view, or social oppression.

# Chapter 3 Literature Review

## 3.1 Introduction

This chapter will review the literature relevant to the research topic. It will begin by reviewing the barriers to work identified in the literature, with some consideration of the varying impact of social policy. This will be followed by an exploration of the barriers to work from a selection of the literature written from the experiences of disabled people and work. Whilst not seeking to evaluate NDDP or PTWP, changes to Incapacity Benefit will be discussed in relation to the impact on DP and work. This chapter focuses on DP in competitive employment, and does not consider the literature on subsidised or supported employment.

As discussed in Chapter 2, there is no uniformity in the definition of DP used in the literature concerning DP and work. In this chapter the authors definition is adhered to when presenting their own findings, or when the findings are re-interpreted, by this author, this is acknowledged in the text.

## 3.2 Barriers to Work

### The origins of exclusion

Barnes (1991) and Borsay (2005) record a history of exclusion of DP from work from the period of the industrial revolution, attributed to the change in the nature and [the social] organisation of work. That exclusion has continued to the present day and DP remain excluded through direct discrimination in recruitment, for example, as they allegedly lack the relevant criteria and skills, ‘in addition to having all of their faculties’. (Dyer, 1990 quoted in Barnes 1991.65). Graham et al (1990) also find direct discrimination by employers in the recruitment process, and less favourable treatment. Employers were ‘continuously placing restrictions’ on the disabled candidate without seeking to establish their ability to do the job.

The research method used two similar [fictitious] applications for work, that differentiated only by disability for one of the candidates, and showed the disabled applicant to be six times more likely to have a negative response. This study was conducted in the private sector. Some gave interviews [not the job] to DP 'only because it was policy', whilst others who employed DP kept them in low paid low status work, or paid qualified people less than their peers (Graham et al, 1990.8).

Walker (1982) considered the labour market disadvantage experienced by young people who had an 'educational handicap'[16]. He highlights the low skills low pay trap that is exacerbated by the fluctuations in the market demand for low skilled workers, a situation prevalent in today's labour market. He found significant statistical differences between the 'non-handicapped' and 'handicapped' young people [the authors terminology] in entrance to primary and secondary sector work, with the latter often being left 'bored' and underemployed in repetitive low paid work of poor status. Walker identified how aspirations in this latter group were attributed to low aspirations of teachers or others in career advice, and how that manifested itself through the internalisation [by the young people], of others low aspirations of them. Walker teases out well other social divisions such as social class for example, that add to the disadvantage and may mean that individuals are placed at a further disadvantage through non realisation of their [educational] potential. What is clear in the findings is that status, self-esteem and life chances gained from work, are closely linked to skill levels and educational attainment achieved, which decree the level of entry into the labour market. DP are disproportionately low skilled for a variety of reasons, for example streamed into segregated education due to a physical disability with resulting poor educational attainment due to low expectations of teachers, and when in high skilled professional work, [often] paid less than their peers.

Walker (1982) found that the disparity between disabled and non disabled young people meant that the former were five times more likely to be unemployed, attributed to the disadvantage associated with disability. Baldwin and Hirst (1994) report similar findings to Walker (1982), that disabled young people are significantly less likely to be in paid work, and when they are, earn less than their peers.

Walker (1982) and Barnes (1991) both describe characteristics desired by employers, such as physical appearance, that disadvantage DP. Some DP do not have ‘conventional body shapes’, or lack self confidence or work experience, and thereby experience biased and discriminatory assumptions [by employers], which act as a barrier to gaining work.

More recent research from Barnes and Mercer (2005.536) find the barriers to work for DP continue to be linked to the social organisation of work and that serves to exclude those with an impairment. This exclusion is not confined to employment and is part of a wider social exclusion created by for example, structural barriers such as inaccessible buildings, inaccessible transport or inadequate access to education and information, all of which have an interactive and cumulative effect. Roulstone (2004) agrees, whilst adding the benefit trap experienced by those with an impairment that have not been resolved by the government initiatives of the national minimum wage (NMW)[17] and tax credits (TC)[18], and may mean some DP are worse off in [low paid] work. Barnes and Mercer (2005), agrees with Roulstone (2004), and Hyde (2000) about the linking and cumulative effects, and critically identifies the linking sine non que of an inclusive education system, which is necessary to provide impaired people with the skills to succeed in obtaining what could be termed a good job, in this flexible competitive world of work.

In sum the exclusion of DP from work has a long history, with evidence of discriminatory practices by employers, skills deficits in DP, and structural barriers, that remain today despite policy initiatives to counter them.

## Benefit System Barriers

Grewal et al (2002) identified 4 key barriers to work including DPs exclusion from education or training, with the corollary of DPs negative perceptions of the type of [low paid] work opportunities that are available to them. The key barrier highlighted here however, is loss of replacement benefits for work that may not be sustainable.

## Permitted Work

Permitted work[19] (PW) was introduced in 2002, and allows people on [contributory] IB to work for up to 16 hours per week and earn up to £78.00 without it affecting their benefit entitlement. PW is initially for a 26 week period and the intention is that it is a stepping stone to full employment. Alternatively IB recipients may work indefinitely for a maximum of £20.00 weekly, or PW may be extended in some circumstances to 52 weeks [or exceptionally more]. Dewson et al (2005) report that customers viewed the gains from PW to be positive and a step towards work, gaining key skills, increased self confidence and motivation, with a greater sense of independence. Beyer et al (2004) identify fear amongst IB recipients that undertaking PW will trigger a benefit review. Stanley and Regan (2003) agree that benefit entitlement may be questioned by undertaking PW. The rules and guidelines state that a review should not be automatically triggered, however the guidance to Decision Makers does provide for a review when any activity takes place which may indicate a change in incapacity, (Decision makers guide, 2006).

Beyer et al (2004) highlight well the diversity of disability which may mean that policies may impact on different impairment groups disproportionately. For example in means tested benefits such as Income Support (IS) disregard rules mean that a maximum of 4 – 5 hours work per week at the NMW may be worked before a reduction in benefit entitlement occurs. People with a learning disability may both need more time to learn job skills and also ‘more than others, need job experience and skills’ (Beyer et al 2004.5). The inflexibility of the IS benefit rules is magnified for those with a learning disability, they are unlikely to qualify for contributory IB, and there is no incentive to increase hours of work as, pound for pound deductions are made after the earnings disregard figure of £20.00 is reached. This acts as a barrier to working more than 4 or 5 hours per week, at minimum wage rates [currently set at between £3.30 and £5.35 per hours dependant on age, from 1 October 2006].

The earnings disregard limit in comparison has not been increased and remains at the same rate as in 2004 when this study was completed. [The permitted work rate is currently £86.00 per week]. The jobs gained were generally low skilled and low paid, with the question of the exploitative nature of low pay raised by one participant (Beyer et al 2004.32). In sum, the rules for benefit entitlement were identified as a barrier to work, as well as a barrier to additional work, with some opting to do voluntary work instead. Roulstone (2004) also finds that low paid work is in itself a barrier to work with the risk of ‘institutionalised low paid work’ with NDDP.

Stanley and Regan (2003) highlight several barriers to work including impairment, the labour market and poor qualifications. The two significant and substantial barriers highlighted are the structure of the benefit system and discrimination by employers and others.

Barnes et al (1998.20) identify two main barriers highlighted by DP. The first is the education system:

> ‘It all begins with education … if you don’t come out with these abilities realised, you start about 500 yards back from everybody else and you spend the rest of your life catching up’.

There is a spill over of the impact of segregated education onto restricted aspirations. The second is a wide range of barriers created by the benefit system including the risk of leaving benefit, and difficulties in obtaining work experience through voluntary or part-time work. Barnes et al (1998) propose a possible solution, to allow DP to work longer hours and earn more pay before it affects their benefit rate.

Stanley and Regan (2003.10) agree that the benefit system may be a significant barrier to work. They highlight the risk of policy confusion created by the governments non sequitor encouragement to IB claimants to seek work, alongside IB benefit rules requiring proof of *incapacity* to work. The tension created for DP further adds to the barriers to work, as they fear jeopardising their benefit entitlement by showing they are capable of or considering work. Also highlighted is the changing profile of IB recipients, reflected by the fact that mental health problems make up a significant proportion of impairments (stated by those claiming IB). This latter point emphasises the correlation of long term fracture from the labour market and consequential disability, as social interaction for example is an important element of work (Gordon, 2002).

In a study designed to consider whether the work related incentives and conditionality in the benefits system were likely to improve outcomes for DP, Stanley et al (2004) find the conflicting encouragement to find work, alongside the ‘test’ of incapacity to be the crux of the matter. The distinction between who is, or not, capable of work makes increased conditionality ‘high risk’ (Stanley et al 2004.vi). They argue for reform of the ‘IB regime’, and question the capacity of JCP to deliver the agenda within their current resources. They further highlight other barriers to work to be, employer discrimination and inaccessible transport. The Cabinet Office (2005) report agrees [with the benefit system barrier to work], and identifies five main reasons why DP find the transition to work risky and complicated, including a fear of benefit reviews.

## Social Capital and attitudinal barriers

Roulstone (2004.197) identifies barriers to work for DP under 4 main headings:

- Personal (social capital);
- Attitudinal;
- Environmental; and
- Governmental (law, benefits and schemes).

Roulstones' categories provide a useful framework, and are utilised in this paper.

Roulstone elaborates on each heading to highlight first, that DP have less skills and educational achievement to offer employers, attributing this to the special education system and low expectation of education professionals and others.

## Education

Despite the 1944 Education Act conceding, where possible, mainstream schools to be the most appropriate environment, disabled children continued to be segregated and leave school with significantly less qualifications than other children.

> 'Nearly half of all disabled children leave school with no educational qualifications, compared to just one in eight of all children.'
>
> (Burchardt, 2004.150)

Low expectations continues to be a problem with SENDA[20] (2001) marking the inclusion of disabled children, for the first time, in New Labour's 'Education' mantra.

French and Swain (2004.169) find that the [education] inclusion agenda ‘is unlikely to succeed’ unless DP are involved in the process. They go on to report mixed views on mainstream inclusive education, and highlight the significant issue of bullying or being labelled ‘difficult’ [in mainstream] due to disability. Goode (2007) considers the experiences of DP in higher education and finds the lack of reasonable adjustment, and the extra burden placed on disabled students to progress access issues, raised the potential of academic failure. Some described their experience of negotiating access to courses, as doing battle.

> ‘The whole of the first semester was a nightmare from beginning to end …. things were finally in place …. six or seven weeks in. By that point I was behind …. I hadn’t done any work, and for obvious reasons it takes me longer to write an essay than most people. (Blind Student).’
>
> (Goode, 2007.46)

Grewal et al (2002) and Burchardt (2000.9) find similarly that DP are disproportionately low skilled, a factor associated with reduced chance of being in work. However, even when in work DP earn less than their peers (Burchardt 2000.12) (DRC, 2006) with gender differences, and also variations due to the degree of impairment, finding that those with greater severity of impairment or with mental health problems fare considerably less well. This latter point reflects Roulstone's second heading of attitudinal barriers.

## ICT’s and Attitudinal Barriers

In his earlier work on disabled people, work and new technology, Roulstone (1998.14) finds that [negative] attitudes to DP are ‘the principal source of many other barriers’. For Roulstone the origins of negative attitudes to DP stem from their exclusion from the means of production with the rise of industrialisation. Roulstone’s study considers the opportunities provided by new technology that may remove the physical barriers to work which are based on aspects of physical strength, dexterity or ‘normality’. The possibilities of ICT’s to enable DP to work in a changed work environment where their impairment is no longer disabling. Stanley and Regan (2003) identify a dichotomy of ICT’s[21] which have the capacity to both include and exclude DP, by reducing the demand for high skilled labour on the one hand, or by affording opportunities through adaptive technology on the other. But are the views about ICT’s cyber optimism or realistic and justified?

Roulstone’s (1998) study reveals that enduring negative attitudinal barriers remain, with the continuing thread of environmental barriers, such as unadapted toilets, or the way things are done around here [job design], and act to often negate the advantages of the new technology. Employees position within the hierarchy of work was seen to be a factor in whether or not individuals had the power to effect changes to their environment or job design. Other barriers such as a lack of ICT training for example, or the software [special] fix for a disabled user, to the [normal] standard equipment, produced another barrier.

> ‘The biggest problem I’ve encountered are voice synthesizers; they range from Metal Mickey to … the voices are very bad, very tinny, always American. One of the systems, I just couldn’t understand a word.’
>
> (William, unemployed programmer, visual impairment; attitude, environmental and technical barriers).

Quoted in Roulstone (1998.104).

Staying with Roulstone (1998), he explores the underlying [left and right] ideologies that essentially divide along a cyber optimistic and inherently deficit or medical model approach of the promise of a technological fix, able to transform the disabling work environment [and DP], to facilitate employment opportunities for DP. The second view is based on the social model concept, and whilst that view acknowledges the possibilities presented by ICT's, success relies on social and attitudinal change to realise the potential posed by ICT's.

A recent survey by the Disability Rights Commission (DRC.2006) found that 81% of [internet] sites failed to satisfy basic accessibility criteria, this included government sites. This governments information age key policy targets include 'Universal internet access in UK by 2005' (Hudson, 2002.517), and their economic agenda is based on competition and supply side principles, underpinned by a belief in the emergence of an information age, whose currency is access to information. What happens in reality for DP is retrofit of a fix to the technology at premium cost, or no access at all. DP are often e-excluded. Goggin and Newell (2003.117) find that for some DP the barrier is *additional* skills, which is a ….

> 'Fantasy: All you have to do is plug in your computer, and it'll be the answer to your access prayers. Fact: Every speech, Braille, or large print method for getting information from computers requires the user to learn an extra skill above and beyond the skills sighted people need. Blind people must know more to get the same work done'. (Goggin and Newell 2003.117).

The analogy of the divide of rich and poor, excluded and included, in work and worklessness is juxtaposed with the digital divide of no access, or reduced access to ICT [in the information society] for many DP, with a correlation of the factors.

### Attitudinal

Hirst et al's (2004) review of data [from the enactment of DDA 1995] on DP in the public sector found that although the numbers of DP employed had grown, there remained a significant gap that was attributed to the extent of disadvantage experienced by DP in obtaining or staying in work. Impairment type differences identified those with mental health problems, of ethnic origin or with learning disabilities to fare less well in getting or keeping jobs, whilst for all [employed] DP there are marked differences in the status or job role held, when compared to non-disabled people, suggesting fewer progression opportunities linked to disabilities. This highlights the attitude and discrimination barriers faced by DP, and the higher level of attitude barriers levelled at those with particular impairments. Particular differences highlighted by gender in this study are negative pay differentials [although applicable to both], with men faring less well, and the differences in occupational status referred to above. This study also considered employers often negative attitudes to making reasonable adjustment for disabled employees.

Specific impairments were identified as a barrier to employment for example, sensory impairment being seen as preventing visually impaired people being employed for computer work.

## Government law and schemes, and the environment

Roulstone (2004.199) final point relates to the workfare approach of the NDDP and PTWP, essentially supply-sideism underpinned by what is seen as weak legislation, from the Disabled Persons Employment Act (1944.23) through to the current DDA (1995), (DDA Amendment Regulations 2003) and (DDA, 2005). Significant criticisms have been levelled at the DDA by disability rights activists, targeted at its medical model underpinnings, its complexity and that it allows certain forms of ‘less favourable treatment’. (Roulstone, 2003).

Roberts et al (2004) found that the DDA was more effective at gaining adjustments for customers than employees. Little consideration was given to reasonable adjustment in the application and interview process, for example, with the public and voluntary sector more likely to employ DP. Many employers felt it 'difficult' to employ someone with a disability, with 33% considering it a major risk, and 'impossible' with particular mental health conditions such as schizophrenia (Roberts et al, 2004.5). Employers found the concept of reasonable adjustment to be vague, with concern for the costs especially amongst small businesses. Adjustments such as car parking space or flexible working hours were reported as easy to do, with adaptations to premises and work environments considered difficult. Large enterprises and voluntary and public sector employers had a higher level of knowledge of the DDA and who would be covered by it, than small businesses.

Most adjustments were made for people with physical impairments rather than for those with less visible impairments (i.e. hidden disability), with 35% of employers.

Dewson et al (2005) national survey of NDDP employers found that the survey was not a representative picture of employing establishments nationally, with a high proportion of public and voluntary sector employers represented. The primary and private sector were correspondingly heavily underrepresented. The commonest recruitment category was into unskilled occupations, and third of the employers surveyed held negative perceptions of increased absence rates, with concerns for lower productivity. The report does not confirm whether these concerns were justified or not.

## Experiences of Work

In a study written from the views and experiences of visually impaired physiotherapists, French (2001) explores the barriers to work, and the strategies used to stay in work. Visually impaired people are disproportionately less likely to work than others within the disability community, with three out of four blind and partially sighted people of working age inactive, and nine out of ten employers stating it would be difficult or impossible to employ someone with sight problems (RNIB, 2006).

DP are also disproportionately under-represented in professional employment, however in Physiotherapy visually impaired practitioners have a unique place in the history of the profession.  Not from the viewpoint of lack of ability, rather that the traditional power balance of the professional ‘expert’ and the ‘dependant’ ill or disabled patient is challenged by a disabled professional.

The acceptance of visually impaired students was assisted by a specialist school run [latterly] by the RNIB[22], and by adapted treatment machines devised by scientists working for them.  The barriers identified in French’s earlier study centre on attitudes, and the changing nature of the job.  Descriptive accounts are given of prejudice and discrimination, for example:  ‘… the first boss I had wouldn’t promote blind people, he was quite open about it’.  (French 1995.10).

Physiotherapy ‘developed from massage which visually impaired people traditionally practised’ Barclay (1994) quoted in French (2001.xi).  However other impairments were actively discouraged in applications predating DDA (1995), and the more recent criteria has a medical model or paternalistic emphasis. Recounting experiences of other disabled health and welfare professionals, from an earlier study, French identified barriers relating to access to, and during professional education, with a general lack of adjustment in course delivery. Attitudinal barriers made it difficult to gain acceptance for training for example, or when qualified, assumptions were made that they would work with disabled people.  When qualified, the areas of specialism chosen [by the participants] were attributed to external limitations imposed due to their specific impairment, with more senior positions associated with the autonomy to delegate work that would be difficult to do otherwise.

Kitchin et al (1998) conducted a qualitative study of disabled people's experience of gaining employment, and the barriers, and potential solutions, to work. Inadequacy of disability benefits, in particular in relation to the additional costs of disability, for example relying on taxis due to inaccessible public transport, was identified as a barrier to work. Lack of suitable and flexible work that meets the need of those with impairments who cannot work full time, or have 'in work' access needs is identified as a barrier, alongside negative attitudes of employers who have limited knowledge of disability. Participants cited employers as discriminatory and fearful,

> 'They see the chair, or they see the disability, they don't see the ability …'
>
> (Kitchen et al 1998.795)

or barriers in physical access to premises.

> 'I'm a qualified legal executive. But I can't get any work. A. because of access, B. because I am a wheelchair user. The majority of the courts are inaccessible.'
>
> (Kitchen et al 1998.797)

Other barriers discussed included a lack of suitable training courses with trainers who were disability aware, and the need for more opportunities for work experience to better equip DP with skills to offer employers.

McLean (2003) reports on employees with Long Term Illness or disabilities in the UK social services workforce, and details and categories the numbers employed by various characteristics, including [medical] condition and health status. Where barriers to work are identified, the heading given is 'the effect of having a long term illness or disability' (McLean 2003). *This* author would interpret the findings as barriers to work, for example, manual lifting causing pain and 'restricting employees activities', would be reinterpreted to a lack of reasonable adjustment in job tasks by allocating that part of the job to a colleague, or by providing mechanical lifting aids. A further example used is ‘those with visual disabilities, were unable to drive or had other difficulties with mobility’. There is no mention of whether driving was an essential part of the job, or whether the workplace had obstacles that restricted mobility for those with a visual impairment. What can be teased out here is that rigid job designs; colleagues and managers negative attitudes; physical access barriers in buildings; and restricted opportunities in career progression; serve to disable those with an impairment employed in the UK social services, when compared to their able bodied peers.

French (2001.117) identified six significant barriers to work experienced by visually impaired physiotherapists, similar to those identified in McLean (2003) and Kitchin et al (1998). Poor public transport and the need to sometimes deliver equipment to patients in the community, presented barriers with the ‘norm’ of personal car usage highlighted. Strategies used to overcome the barrier were variable, with Access to Work[23] (AtW) help with taxi fares identified as a key support mechanism. Burchardt (2000) listed characteristics associated with an increased likelihood of work, and car access was included.

The second barrier concerned use of new and more complex therapeutic equipment. The strategy used by the physiotherapists to overcome this barrier is possible due to the autonomy of choice of interventions that professionals have compared to DP in unskilled work.

The third was administration which presented dual problems of increasing volumes of paperwork, this barrier is compounded by colleagues negative behaviour. Of those who elicited support through AtW many found the support provided not of good standard, or the system fraught with delay or unhelpful staff.

The fourth barrier identified is the physical environment and finally a barrier that has been discussed in many other papers reviewed here, behaviour [and attitudes] of colleagues.  For Roulstone (1998, 2004) negative attitudes are the source of other barriers.  For French (2001.140) the findings were mixed with some reporting supportive behaviour from colleagues.  For others this was less so and ’17.7 per cent reported discrimination and harassment from other physiotherapists, 24.4 per cent from managers and 8.9 per cent from other health care workers.’

Particular strategies used were minimisation [of impairment and the disabling effect] or passing as normal was used as a tool to deflect discrimination and encourage acceptances.  Compensation is used to try and work harder, be better and so reduce the opportunity for criticism related to the disabling effects of the impairments.  Openness was used to avoid embarrassment or problems arising reportedly getting easier with time and more senior positions, as it was then seen to be less risky, reflecting similar findings in Roulstone et al (2003).  The internalisation of others questioning of the abilities of the visually impaired physiotherapists led to feelings of ‘inadequacy or fear’ that the author could not attribute to a social model barrier, but nonetheless arose through the attitudinal barriers experienced (French, 2001.144).

Roulstone et al (2003) approach the issue of barriers to work by identifying the strategies and support DP use to gain and stay in work.  Barriers to work identified centre on a ‘lottery’ of provision within AtW, and the administrative process that leaves DP starting jobs before the necessary equipment or support is provided.  AtW is described as a key support mechanism for DP in work, however the delays and at times limited support provided, create barriers to work. Participants felt that more awareness of the diversity of disability generally was needed for JCP staff, colleagues at work, and employers.  Other policy related barriers identified for those with a learning disability in particular, were the inflexibility of the benefit system which made a meaningful amount of work not possible without loss of essential benefits.

The use and availability of ICT’s was viewed as positive and enabled DP to choose which medium to use, thereby removing some barriers and giving flexibility to the user.  Strategies used by participants varied, and were dependant on the circumstances and the employer, with organisations of and for DP singled out as good practice employers, who provided a supportive environment.  Some participants used minimisation of their impairment or ‘appearing normal’ to avoid barriers or failure to make adjustments, whilst others used assertiveness techniques to good effect.  The former strategy suggests employer attitude barriers and discriminatory practices.

This chapter has outlined the barriers to work experienced by DP.  The evidence provided shows a dichotomy of views between the governments dependency culture view on the one hand, whilst the evidence of poverty and barriers to work suggest oppression and exclusion.

The following chapter will outline the methodology of the research study, which was designed to explore DP’s views of the barriers to work.

# Chapter 4 Methodology

## 4.1 Introduction

This study was conducted with the aim of exploring the barriers to work for disabled people, from their own perspective and circumstances.  It was hoped to discover what motivated them to work, what they saw as the barriers to economic participation, and how they viewed their contribution in a society structured around the job role.  This study was underpinned by the social model concept of disability, reflecting the aim of conducting emancipatory disability research.  The method chosen was a qualitative study, as the most appropriate to ensure a suitable fit between objectives and method.

## 4.2 Choice of research design

Qualitative research is a strategy that emphasises and focuses on, the complexity and detail of social situations from the individuals perspective.  It is underpinned by the philosophy of phenomenology, which is concerned with individuals and how they see and experience the world (Bryman, 2004.13).  The starting point of this work is the experiences and views of DP and the barriers they face in employment.  The complexity and diversity of impairment and disability, and how it is experienced by individuals and in particular in the world of work, makes qualitative research an appropriate methodology for this study.

A qualitative study allows a detailed exploration, to gain an in-depth and rich account, with the flexibility to follow up points of interest that emerge in the process. (Bryman, 2004), (Snape and Spencer, 2003).  Qualitative research aims to provide in depth understanding of individuals experiences in the context of their own personal circumstances, and is characterised by exploring phenomena from the participants perspective.  It is a mainly inductive [rather than deductive] process, using unstructured methods, which generates rich and complex data, and analyses the data in the form of words and descriptive accounts rather than numbers or statistics.  The flexibility of qualitative research also lends itself to retaining diversity and complexity in the analysis of the data, as well as identifying themes and patterns.

There are many different ontological and epistemological positions within the field of qualitative research, with no universal method of conducting qualitative research.  Interpretivism is seen as integral to the qualitative tradition [as opposed to positivism], requiring an awareness of the role and perspective of the researcher (Snape and Spencer, 2003), (Bryman, 2004), (Silverman, 2004). Qualitative data presents findings relating to the micro [rather than macro] level, with attention generally paid to emergent theories, rather than a priori ideas.

Qualitative research is also viewed as compatible with feminist research, as emancipatory, and in keeping with feminist principles and should ‘alleviate the conditions of oppression’ (Skeggs 2001.429, quoted in Bryman, 2004. 288). Similarities may be drawn with emancipatory disability research, with the flexibility of design enabling a process of participation in objectives and outcomes, and feedback in the reporting of findings (Zarb, 1997), (Barnes, 2004).

In summary a qualitative method was chosen for this study as it would allow an in depth exploration of the experiences of disabled people in work, giving them the opportunity to express their views on the barriers they experience to the world of work, and participation in the reporting of findings.

## Research Design

The research design was cross sectional and the method chosen to generate that data was 12 semi structured in depth interviews.  Lewis (2003.58) describes in depth interviews as ‘the only way to collect data where it is important to set the perspectives heard within the context of personal history on experience”.  Further that in depth interviews facilitate the detailed focus necessary for ‘understanding motivation and decisions’ both key objectives of this study.  This type of in depth face to face interview normally takes place at a location convenient for the participant, and this satisfied another key requirement for this study, to ensure accessibility of venue for participants with mobility or other impairments.

The implication of this choice of research method were ensuring accessible  and private venues for participants; ensuring suitable and willing participants; the time needed to plan and execute the interviews, and to transcribe and analyse the data obtained.  The planning stage needed to take account of the availability of willing participants, of the researcher, and the availability of accessible venues, in locations suitable for both participants and researcher.  This added a particular dimension to the study as some venues had to be accessibility checked before use, and meant that a time cushion was built in to ensure that the entire process could be concluded timeously.

## 4.3 Sampling Approach

In qualitative research the sampling approach is purposive [in contrast to positivist research], rather than statistically representative.  The aim is for the sample to be reflective of the particular features or characteristics relevant to the topic under investigation (Lewis, 2003), (Bryman, 2004).  Qualitative sampling is not concerned with determining the wider incidence of the characteristic or phenomena under investigation, and therefore large samples are not necessary.

### Study Population

The first stage in the sample process involved identifying a suitable study population.  The most important criteria is the proximity to the research subject (Lewis, 2003).  The chosen study population were the students past and present, and former and current employees of Newlink.  The sample frame was drawn from an existing source of data of [self identified] DP, with aspirations of and experience of work who were; registered with Newlink; who had previously been registered with Newlink; who were employed within the project; or were known to have moved on to outside employment. The researcher sought permission from the Board of Trustees at an early stage in the planning of this work. The Board of Trustees gave permission for the study to be conducted. The management team [of Newlink] discussed with the researcher the positive use of the findings from the research, this included discussions with the participants. An agreed outcome was a separate executive summary document to be produced by the researcher for use by Newlink, to further the objectives and interests of the members of Newlink. This executive summary does not form part of this work, however may be viewed in addition to the findings made. The Chief Executive of Newlink liased with all individuals to ensure that they were in agreement with the release of their contact details to the researcher.

The researcher followed up the approach from the Chief Executive with announced visits to Newlink sites, to be available to talk through any issues or concerns on a one to one basis, including any alternative format or other access needs. This also allowed students, who had not previously recorded a wish to engage with work related activities, to nominate themselves for the sample frame.

### Purposive selection criteria

The sample frame was then examined to select for relevant characteristics of experience of work. The definition of work was purposively selected to mean; full and part time employment in the voluntary, private and public sector; full and part time unpaid work in the voluntary or third section. This characteristic was considered as a primary characteristic. A second primary characteristic was impairment, and a range of impairment was purposively selected to reflect the diversity of disability and the differing impacting barriers to work. Selection for impairment was not considered to be inconsistent with the social model underpinning of this study as it was an essential criteria of the work. Further to borrow an analogy from within the disability studies debate on defining the social model; if an individual does not have an impairment then consequently there will be no disability or disabling barriers, as one cannot exist without the other.

The other variables considered in the selection criteria were age, gender, and family status, to ensure a balanced sample. Due to patchy information held on ethnic origin, this criteria was not considered in the selection process.

A sample frame of 64 was obtained from this process, and invitation to interview letters were sent by post or e-mail, with an opt-in clause to facilitate positive and active consent. The invitation letter is reproduced as Appendix 5. The invitations were sent on University of York headed notepaper, with a return envelope addressed to the University, and for e-mail versions the researchers York University e-mail account. Care was taken to ensure alternative format options were provided for those who had indicated this was needed.

A high response rate of 80% meant a further selection had to be made to reduce the numbers to a more manageable number of 14.

## 4.4 The interviews

The interviews took place over a three week period in various venues across the East Midlands. There were two last minute participant withdrawals, and therefore twelve interviews in total were conducted. It was decided at this point not to revisit the sample frame, as all twelve interviews had produced a large amount of rich data. Appendix 6 shows the characteristics of the respondents, and shows an even number of men and women, with a range of ages across the working age range of 16 – 65. This information is provided to explain the composition of the sample however it does not purport to hold any statistical significance.

A topic guide was prepared for use in the semi structured interviews and is reproduced as Appendix 7**.** The topic guide was trialled with two volunteers from Newlink before the study commenced, and some minor amendments were made at this point, to reflect the comments made. The topic guide provided a framework for the researcher, with questions grouped in a particular way to cover relevant themes. However participants were allowed to dictate the order of the themes, dependent on how they responded to a particular point, or overlapped in to another area. In other words the guide was used essentially as that, not as a rigid structure or question and answer session. Flexibility was retained at all times, with open ended questions and pauses to allow reflection, or to follow up points made not covered by the topic guide. All interviews were taped with the participants prior permission, and confidentiality and anonymity was emphasised both before and after the interviews, to put participants at ease. A spare tape recorder was carried to each interview, however was not needed.

In several cases participants continued talking after the recorder was switched off, making relevant comments which were recorded manually. Time was also taken after each interview to reflect on the process, and to provide time to deliberate on the interview technique, and any learning points gained. The question of possible bias created by the researchers position within Newlink, [as Chairman of the Board of Trustees], or as an employee of JCP may be a factor that should be considered, as although the independence of the research from both JCP and the Board of Trustees was emphasised, it is still possible this may have affected responses.

## 4.5 Data Management and analysis

The next step in the process was the transcription of recordings to hardcopy. Verbatim accounts were made, and any contemporaneous notes taken were added to the text, annotated as such. The researchers observations of particular emphasis given, through non verbal cues for example, were also recorded to be used in analysis of the data. The text generated was examined in depth to ensure a thorough familiarisation.

A method was sought to capture the richness of the data generated into key themes and concepts. A manual matrix based model, with defined rows and columns was chosen, which used a thematic approach to classify and interpret the data. A conceptual index (see Appendix 8) was employed to capture the important themes and concepts identified in the data analysis, to enable essential patterns to be found. The conceptual index was crafted from initial familiarisation with the interview transcripts and the topic guide. Further iterative trawling of the data threw up some additional categories, and the final index was applied to the data, using coloured pens and coded numbered paragraphs. The ordering of individual cases on each of the thematic charts, was kept consistently the same to ensure that cases could easily be reviewed as a whole. Coded chunks of texts in summary form, covering salient points, and with quotes identified, were transferred to the matrix. A further distillation to a summary for each theme, and each case was undertaken. The original page reference numbers were entered for the text captured on the matrices, to ensure a rapid return to the original raw data was easily achieved. This method ensured ease of analysis within and across cases and themes, and ensured close contact with the original date was maintained.

In summary this chapter has detailed how the research study was planned, organised and executed. It has detailed how the data gleaned from the research was managed and analysed. Chapter 5 will now examine the generated data, and the analysis, in more detail.

# Chapter 5

## 5.1 Introduction

This chapter will explore and present the findings from the empirical study on DP's experiences of work gained by working closely with the data to identify emergent themes and concepts, and by exploring links in the data. For the purposes of this research the definition used of the key concept work, was taken to be any activity involving mental or physical effort that is paid or unpaid, within the public, private or voluntary sector. All of the participants were currently engaged in work activities covering a range of full time and part time remunerative work in the private public and third sector, and part time work in the voluntary sector. The participants of this research defined the concept of disability in relation to the barriers to work, by self identifying as having an impairment, that [for them] results in a disabling effect when engaging with work activities or settings. Other key concepts used, such as the social model paradigm of disability have been defined and discussed elsewhere in the text, and are not repeated here.

The remainder of this chapter will now present a descriptive and explanatory account of the findings, gleaned by working through an iterative process, deductively and [primarily] inductively with the empirical data

It is intended that this study will add to the [economic exclusion] debate by exploring the working experiences of DP at the micro level, and it is hoped to inform and develop emergent theoretical perspectives on DP and their economic exclusion. In particular this study aims to explore the context of DP's exclusion from work, in essence to explore the dichotomy of social oppression or dependency culture view.

If the [dependency culture] view is to succeed it is in itself dependant on two other factors; namely that those who want work but don’t have it have access to jobs in the market place; and that the individual is purely motivated by his own financial need.

## 5.2 Key Themes

The findings are collated under five key themes which cover: personal details, motivation and aspirations, barriers to work, enablers and strategies, work or welfare. To preserve the anonymity of participant and where quotations are used, specific identifying details of names and location have been omitted.

## 5.3 Motivation/Aspirations to Work

**Motivation:**
The early part of the interviews gathered views of what motivated the study participants to work. This generated data which identified five main reasons for wanting to work, namely: financial reasons, psychological reasons, interaction with others [social contact], gaining experience, and achieving ultimate job satisfaction. Participants typically had more than one reason for wanting to work, with primarily one key or dominant feature, with other additional features mentioned less strongly.

The common factor to emerge between all respondents was self esteem and self worth, with all participants strongly identifying with this reason, and a recurrent thread of increased self confidence as a result [of working].

> ‘I am not able to emphasise enough how good work is for me…. it is about self fulfilment. To be recognised as something, not just somebody who got, who is disabled, you know, a disabled chap who doesn’t work …., I think all people have a basic need to work or to do things they value that’s

> recognised.  Not being able to do those sort of things is very very undermining, of people's self worth.'

Others linked self worth to the rewards from job fulfilment.

> 'There is reasons for living …. and that's what this is …. this feeling …. it makes me feel that I'm not useless, I'm not stupid, and you feel as though you are, specially when people talk over you [when you use a wheelchair] …. now I teach, I can teach you that, you know, and that's rewarding.'

For some self esteem was linked to enjoyment [reward] of the particular role or job performed, alongside the social contact that afforded.

> 'It's the job I've always wanted to do.  I actually want to work, and I enjoy going …. and I mean being with people, socialising.'

Closely linked, for a number of participants, to feelings of self worth was the stigma felt by being in receipt of benefit.

> 'You read the papers or listen to the news …. unemployed scum, even though they can say we don't mean you, you know, not people like you, you deserve your benefit ….  everybody's bunched in together as sponges.'

A common factor that emerged for those not primarily motivated by financial reward was the lack of real difference, financially, between working or not.

> 'I mean I don't think it's financial, cos I was no better off taking the job really.'

Respondents within this group tended to be working voluntarily to try work, or for benefit related reasons; to be working part-time for impairment or disabling barriers reasons; or to be in receipt of means tested in work benefits, for example Tax Credits.

The importance of money for all of the participants ranged from not being particularly important for half of the respondents [reflecting the in work poverty trap], to more exceptionally, to be the key motivator, with often secondary self esteem reasons.

> 'It's kind of, the reasons are exactly the same as for people who are non disabled and its kind of like, its like people work because they need money. Plain and simple. Obviously there's essentials that they need money to live, and obviously many people with families want to support them as well. You've got social reasons as well, meeting people and I think, but more about identity as a person.'

Further analysis of other factors at play for the exceptional few here found that those most likely to state financial reasons to be the key motivator were more likely to be employed in competitive remunerative work in the primary or public sector; employed at a professional or high skills level; to be working full time, and not to have been in receipt of a means tested benefit prior to securing the job. What may be concluded from this is that the financial gains were significantly higher than for others [in the study group], and that there was a clear work history, as contribution based benefits, or no benefits, had been paid prior to starting [their current] work. This group was more closely and actively connected to the labour market.

A number of participants worked across sectors, some combining voluntary and remunerative work, to add to their skills.

> ‘I do like to do jobs where there is the opportunity of learning new skills, and slightly different kinds of experience. As a volunteer with …. I felt more that I was valued, my skills were recognised, and I learned new skills.’

Some viewed their current or previous voluntary role as a stepping stone to remunerative work.

> ‘You can’t just go from 10 years not working, on benefit, and go straight into [remunerative] work. So I did it voluntary just to see what the job was like really, then took it part-time for a start, so it was good to just do it that way. Now I work full time. It wouldn’t have worked otherwise.’

For some voluntary work was preferred due to a fluctuating impairment, as remunerative work was not considered to be an option.

> ‘Volunteering is enjoyable, and one of the things about volunteering is if you feel really bad one day you can ring up say I’m sorry I can’t come in. They understand because they know [about impairment], but an employer wouldn’t [understand].’

**Aspirations:**

The respondents described a range of hopes and ambitions for work that may be broadly grouped into four. The first shared characteristics of a clear career plan, often coupled with high academic achievement.

> ‘I have aspirations to achieve things …. I have ambitions just like everyone else [non disabled].’

The second group shared common experiences of discriminatory behaviour by employers or colleagues, or physical access barriers with lack of adjustment in what they termed ‘outside employment’. By this they meant work outside of their current role [in the third sector], and in particular in competitive work environments [in the private and public sector]. They were discouraged to try ‘outside’ work, and had reduced motivation and aspirations as a result.

> ‘I found jobs hard work, actually it was getting in the building and getting to my desk …. you don’t always get the help you need …. they say they will, but they don’t really. It doesn’t materialise [accessible building]. And it’s the facilities [toilets] that was no good, not the job [wheelchair user].’

Some described meeting persistent external barriers that had a drip drip effect of lowering their self esteem, and their motivation. This had often resulted in leaving the job.

> ‘ …. to take that all the time [no adjustments] and keep going is tough. It makes you realise the way people have been thinking of you, seeing you, that’s how they see you [as a problem].’

The third group comprised of those who had aspired to a particular job or role, and having succeeded in getting the job, were satisfied with that.

> ‘To keep this job permanently – it’s the job I want to do.’

The fourth group comprised primarily of participants who had been in work when they developed an impairment, or when their impairment changed, or they met discrimination. They had been away from the jobs market for several years. The [recent] positive change in their aspiration status was attributed to, positive experiences of the work environment and attitudes [of others] in their current [job] role.  This group worked in the third sector, in both voluntary and remunerative employment, and primarily in an organisation of DP.

> ‘I would probably try and [do remunerative] work in the voluntary sector, now I’ve started doing it again [work], it has encouraged me, got my confidence back.’

A recurrent theme across this section dealing with motivation and aspiration is the reported relative ease of obtaining reasonable adjustments in the third sector, both when engaged in voluntary and remunerative work, or when working voluntarily in the private and public sector as compared to remunerative work in the private and public sector.  This was attributed to come down to a costs benefit analysis, when doing voluntary work.

> ‘The deal is, I give my time, and at the same time gain the experience I want.  It’s just to get experience because I’m finding it impossible to get paid pharmacy experience otherwise, what they get is my time for free, but the hours are down to me.  Because of that [benefit to them] I feel they provide the things I ask for, which is not much really [a chair and flexible hours].’

When in remunerative work in the third sector, this [ease of obtaining adjustments] was attributed to the cultural differences between the competitive work environment, where it came down to a real or perceived negative costs analysis; and to a widely reported culture of valuing difference [in the third sector].

This section has detailed the factors that motivate this study group to work, and what aspirations they have for the future.  The following section will consider the barriers to work, a theme that was intrinsically interlinked with motivation and aspirations.

## 5.4 Barriers to Work

A range of issues emerged under this theme that may be broadly grouped into four main categories: Accessing the Labour Market; Attitudinal; Benefit System and Institutional Barriers; and Structural and Physical Barriers.

### Accessing the Labour Market

The features that participants saw as important were education and the job application process, each is considered in turn.

A significant factor for a number of participants was poor access to education at both elementary and advanced level, which created an immediate barrier before entry to the labour market was considered. It is of note when compared statistically to DP nationally [discussed in Chapter 2], this study group shows a higher profile of educational attainment, with all respondents having qualifications at further or higher education level. [Education history is detailed at Appendix 6]. The pathway to these qualifications is discussed more fully later in this paper. The other factor that should be considered here is the nature of Newlink as a training organisation of disabled people. The ethos of Newlink is to provide accessible training, education and developmental [work] opportunities within a supportive environment. Participants made comparison with access to mainstream education for qualifications gained elsewhere.

The participants experiences may be further broadly divided into two, those who experienced segregated education, and those who went to mainstream schooling.

### Segregated schooling

The former felt considerably disadvantaged by a system that focused on a medical model approach at the expense of educational attainment. It is worth quoting extensively on this point.

> ‘ …. the emphasis was on making me walk normal, not on letting me find my own strategies to live as me. I cannot walk normal, never could do, never will, but I had 3 days physio [therapy] each week and 1 ½ days schooling. They just told me to sit at a desk and do what I liked. I was barely literate when I left – could just about write my name. So how can you compete from that.’

Some had a different path and had moved from mainstream to special needs schooling, and at times back again, or used a mix of models [including private education] to achieve their goals.

> ‘I think, I mean to be honest its an up hill struggle for you if you have a disability, a struggle just to get [an education]. It was a whole sort of fight with the education authority, cos I was disabled and had potential. I was being labelled [by the school] as a non achiever, as my statement of needs was basically inadequate. I was also bullied as I was different. And I think an awful lot of it was my parents actually fighting to make sure I had the professional support that I needed, so I could show my potential. It helps that my mum’s a teacher in special education needs, so knows her way around the system.’

It is worth staying with this particular individual to note that from starting in mainstream education where the ‘support’ was reportedly ‘just not there even if they say so’, moving onto special education worked for a time, as the particular school had ‘specialised technology’ which was essential, and equally important [the school] provided an environment free of bullying [due to his physical impairment]. However there was a culture of low expectations [of teachers] for further academic opportunities, and limited access to the full curriculum. To gain access to the full curriculum needed for University entrance, private education was used to both top up and later complement that provided by the ‘special’ school.

**Mainstream**

In the latter [mainstream] group the idea of having to ‘fight for access’ was a recurrent theme for those who had an impairment.

> ‘At the age of eleven my parents had to fight to keep me in mainstream secondary school, as the authority wanted me to go to a special school. But I wanted to sit exams.’

Others found that although they went to mainstream school, no appropriate adjustment was made, and that resulted in no school leaving qualification.

> ‘….. my visual impairment was picked up on the school medicals when I was in primary school ….. I didn’t get any qualifications before I left school because my sight was deteriorating so that I wouldn’t see. They brought me nearer to the [black] board and nearer to the board but it didn’t work. It doesn’t work [for me] if you just make things bigger. It doesn’t help, it doesn’t make any difference. And I struggled. And later when I went to ….. College it took 3 weeks [after the course started] for my [speech] software to be loaded onto the laptop. I had to rely on my memory to follow the course. It was frustrating again [to not be able to access course material].’

For some physical access issues caused by no lifts or broken lifts, or inadequate parking resulted in no access.

> ‘It was up to me to check if the lift was operational before I went [to night school]. Often it wasn’t and I had to miss class.’

### Higher Education

Those who had experienced higher education found a similar pattern of little or no adjustments. Some struggled on without adjustment, whilst others found that they were labelled as a ‘problem’ if they persisted in pursuing their needs or labelled as failing [academically] otherwise. Where their institutions had disability services for students, they were under funded and although they had good policies on paper, they were not followed through.

> ‘…. support in universities isn’t really there for me. I found disability services more obstructive, they don’t actually help with finding people [to scribe in lectures], they might help with filling in a form. They don’t look for ways round things. I’ve ended up employing somebody directly myself [to scribe]. Had a whole fight with them over that, they insisted it had to be students, and that’s not true.’

The experiences of accessing education are presented diagrammatically at Appendix 9. In sum, those who experienced segregated education, only exceptionally went on to achieve academic potential through the use of a segregated, mainstream and private mix. All others who experienced segregated education left school with no qualifications. To gain qualifications later on, a mixture of mainstream and social model based accessible education [in Newlink], resulted in academic achievement.

For others who experienced mainstream schooling, the outcomes were dependant on an accessible environment and the provision [or not] of reasonable adjustment [alongside other social factors and individual potential].

### Job Application Process

A universally reported barrier to accessing the labour market was the application and interview process. The issues here ranged from inaccessible format for the application process, to no interview when an impairment was declared. Some participants, after many unsuccessful attempts, tried not declaring their impairment on the application form, and had an immediate and significant increase in interviews, but not the job.

> '….. as soon as they saw the person on sticks [at the interview], they were not interested sort of thing. You know by the questions you are asked.'

Others found direct discrimination at the interview process, and did not get the job.

> '….. I asked them [at the interview] if they'd got any questions [about my impairment] and they said no, everything was fine. But when they got my support worker on her own, they started quizzing her, you know this is typical, cos she's able bodied and I'm disabled.'

Exceptionally, challenging direct discrimination, using the DDA worked to an extent, although not entirely satisfactorily.

> 'There was no place to state on the application form, to say about adjustment needs, which I thought was wrong. Anyway I got a letter first saying I had the job, then a phone call saying yes, and that's when I said about my adjustment needs. Then the Human Resources called and said I might not have the job, that I needed a medical first. Then they tried to withdraw the offer. …. that's when I had to use the legal thing. It ended up I didn't get the same [role] as everyone else, and my start date was delayed.'

Of interest here were the different experiences of those who had a late onset of impairment when compared to their previous experience of obtaining work.

> ‘I didn’t realise it [impairment] would affect my job prospects, I suppose I just thought I would get another job. ….. Now I don’t hold out any hope really of getting a job. It’s been 3 years now, and I have had one interview, but not the job.’

The above quote came from a Chartered Physiotherapist who had no previous experience of unemployment. When she acquired an impairment [age 49] her employer ‘voluntary’ retired her after her first ever 2 week sick absence. Previously her employment history spanned the public and private sector, part time and full time, and latterly she had been employed by a blue chip company on a full time basis. The only difference she could see, was the fact that she now had to declare an impairment on the application form. This greatly affected her feelings of identity and self worth.

> ‘…. because you know they would do anything to keep people in work, you had to be dead before you could get early retirement normally, but with me it was a breeze, it happened within weeks. And now I’ve become this non person, invisible, that’s how it feels.’

**Attitudinal**

This study participants reported widespread discriminatory attitudes in education; from colleagues and managers in work, and generally felt stigmatised by their impairment.

> ‘ ….. the barriers that I have found in just everyday life is actually getting into places. …… the attitudes from people in the street is you become

> invisible and treated as inferior, and it upsets me. But since I got depression the stigma around that is worse than in a wheelchair, people fear you.’

The range of issues that emerged covered direct discrimination; bullying; ignoring and being treated differently from the outset of impairment; feeling stigmatised; labelled as a problem; stereotypical assumptions made; overly scrutinised and unfairly compared to others [non disabled].

When considering the barriers experienced under this heading the study group may be divided into two. First those who experienced onset of impairment in adulthood, and second, impairment present from birth. Each will be considered in turn. The first group compared their experiences before and after the onset of impairment.

The following illustrative quote captures many elements of the above categories.

> ‘I was diagnosed with …. at which point I acquired a new line manager. At the same time I had my first two weeks off sick ever. I asked for an [occupational] assessment and when the report came back with recommendations on, she [line manager] was visibly furious with me, and unprofessional. She said no [reasonable] adjustments could be made, I couldn’t work at home, I couldn’t reduce my hours, and I could not transfer to the another side of the business. I was made to feel incompetent for asking for clerical help, and from then on if I was in the staff room making a coffee on my own, and she came in, she would turn and walk back out again. She would not acknowledge me or be in the same room as me, unless it was for a meeting. She questioned my judgement and by-passed me and consulted a junior member of staff instead. …. [the company] had good policies it could tick all the boxes, but human resources just stood back, as did other managers and colleagues. I must be thick as a

> brick really, because I knew about the DDA in a vague way, but it was for disabled people and I would not consider myself disabled at that point. She just pushed me out [of the business] and got away with it.’

Having an invisible disability was seen as a double edged sword with the ‘benefit’ of allowing the individual to use strategies such as ‘fitting in’ or ‘appearing normal’, thereby avoiding discriminatory behaviour. This could also have negative consequences, as is illustrated below.

> ‘When I was diagnosed with …. I desperately wanted to keep working, but my employer point blank refused to alter anything, like less hours or different tasks. Because my disability is invisible, I was treated as if I was skiving. I then got depression …. and the stigma from that is worse than MS.’

The experience of onset of impairment across this group typically led to lowered self esteem, ranging to clinical depression. Those who experienced intellectual impairment reported increased feelings of stigma and alienation, as they were treated with fear and often hostility by others.

The second group experienced negative attitudes for as long as they could remember. Being different was always identified with negative attitudes from others and being treated as inferior.

> ‘I was bullied [at primary school] and it was just because I was different, and it was very severe and it made me withdrawn and I was not achieving.’

Being treated differently [to do with impairment], then having to on the one hand identify with the disability category to trigger adjustment, and at the same time defend *ability* to do the job, created a barrier for some.

> ‘I was the only candidate that had to have an occupational health medical [to get the job]. And the doctor was pretty much accusing me of lying on my application when describing what [other work] I had done. It was like you want these adjustments and have this disability, so defend how you are going to be able to do this job, and not be off sick all the time.’

For others negative stereotypical assumptions were made, equated with physical appearance.

> ‘I’m just seen [by colleagues] as not outgoing or confident when I feel I am, but people [colleagues] pick up the impression that I’m not and that I haven’t got the skills, which I have but they don’t realise that.’

This stereotyping led to a ‘lack of progression’ and ‘underemployment’ for the skills level held.

Others found that they were pressured to ‘fit in’ to the culture, which they sometimes could not physically do. This resulted in negative discriminatory comments from colleagues and managers, about doing tasks differently [to other non disabled staff], and consequential lowered self worth and motivation.

> ‘…. people find it difficult that I can’t always work as fast or in the same way as them. They are judging you and comparing quantity not quality issues. ….. I still find one or two making remarks about it [impairment] and about the [physical] way I do things and it is a barrier but I try and ignore it, when perhaps I shouldn’t. ….. It gives me a shock when it happens because I think perhaps I’m fitting in well, and doing the job well and then it pulls me up and it brings me down.’

## Benefit System and Institutional Barriers

The common factors identified were the benefit system, and the lottery of Access to Work (AtW) provision.  Other factors include the lack of information and knowledge of the DDA; and [the provision of] JCP services.  Each will be considered in turn.

### Benefit System

The study group responses differed for those who were in receipt of a means tested benefit such as Income Support or in work tax credits, and those in receipt of [contributory] IB and/or DLA.  The former highlighted the poverty trap of withdrawal of in work benefits [Tax Credits] as wages increased, meaning for them little significant difference in income was achieved by working.  For those in receipt of Income Support the earnings disregard limit of £20.00 resulted in most opting to do voluntary work instead.  The features that this group saw as important were the fact that [predominately] they were unable to work full time for reasons to do with their impairment or other disabling barriers, with consequential lowered earning capacity; some had to restrict their hours to less than 16 and therefore could not claim Tax Credits or have AtW provision; and the earnings gained from part time [and often essentially low paid] work were less than the benefit rate, pushing them further into poverty, if they chose work.

> ‘ …. this lady came in from …. [JCP provider] and she was talking about it [work], and she went through a few jobs I’d like to do.  She drew up a weekly tax credit thing and I looked at it and thought well yes I probably come off with £40.00 more.  But that was working 22 hours a week and I knew I could never work that much.  So she said probably better to do voluntary work.’

The significance of the additional costs of disability combined with the likelihood of low status low paid work resulted in part time work being in work poverty, replacing on benefits poverty.  Participants also feared jeopardising Disability Living Allowance (DLA) payments, by starting work.  Although DLA is payable whilst in work, some study participants had experienced ‘benefit reviews’ directly as a result of taking up a small amount of paid work under the £20.00 disregard limit, or when starting permitted work.  Participants in receipt of contributory IB, generally considered the benefit system more favourably, due to the permitted work rules allowing earnings and benefits to be paid simultaneously, increasing the financial reward.

The fear of benefit reviews, or fear of not being able to return to benefits if the job did not work out was commonly held across the study group.  The fear of losing benefits to try work in what was described as an often hostile work environment, was seen as ‘too risky’ and ‘ stepping in to the unknown’.

### Access to Work

Seen as both a positive key policy, and having an often negative impact in delivery, AtW was described as a ‘lottery’, unresponsive, and bureaucratic procedurally.

> ‘All the forms had to be handwritten, and I’ve got, if you’ve got writing problems yourself that gives you an access problem for a start.  And the way it [AtW] works is I have to claim it every single week, so these forms were to be filled in every single week and then I was paying the taxi company [who would not give an account due to slow refunds from AtW]. I was having to carry £30.00 everyday, then pay the taxi and that’s quite a lot of money, £150.00 a week …. it was just a summer placement, I was only getting the minimum wage, so if I didn’t have my parents to support me, I wouldn’t have been able to do the placement, cos I wouldn’t have

> had the money …. It was just a nightmare …. I was getting my money, the first amount of money back [from AtW] 8 weeks after the placement, and that only lasted 6 weeks.’

The additional critical factor here for this participant was the fact that without work experience placements during the University vacation periods, he would be ‘unemployable’ on graduation, as the [pharmacy] course was built around mandatory work placements. [The University worked in conjunction with businesses and the National Health Service, to provide work placements for students. Despite consistently performing in the top quartile academically, this participant was often unsuccessful at internally organised paper based [job] applications, and had to arrange his own work placement, with consequential increased travel issues].

As with the DDA, information about AtW was perceived as ‘not getting through’ to both DP and to employers.

> ‘I’ve heard of them [AtW], but I don’t really know much about them. I think a bit more information would’ve been helpful.’

Lack of awareness about what help AtW could provide was widespread within the study group, and a commonly held view was that employers also lacked awareness. Those who had experience of help from AtW described a ‘lottery’ of provision, depending on the individual AtW advisor, with the rules being differently applied in different geographic areas. A recurrent theme was the additional barriers caused by; having to approach the employer for a contribution to the [AtW] costs, in what was described as often an already ‘awkward position’; and the extra burden of obtaining, for example, taxi quotes and keeping up with the administrative process.

**The DDA**

The common factor to emerge was the lack of the participants and of employers knowledge of DDA.  A recurrent theme was who to approach for help and advice on rights to reasonable adjustment (RA) at work, in particular when an impairment started or deteriorated.  Participants described this as the necessary information ‘not getting through’ to both DP and to employers, with DP having to instigate requests for RA causing a barrier in itself.

> ‘…. I mean, that’s probably if I kicked up a fuss then they probably would [provide a parking space].  But I don’t want to do that.’

Some who lacked the confidence to ask for adjustments, had resulted in them leaving the job.

> ‘It would be up to me to ask for any adaptation or changes in procedure, and that’s often quite difficult when you’re trying to prove yourself in a job, you feel it might look negative and not look good for you.  I’ve changed jobs sometimes because I’ve reached a certain barrier that I feel that I’m not going to get over, and maybe it’s my fault for not speaking up about it, but I don’t feel confident asking for it.’

A widespread view was the concept of what reasonable adjustment meant, or how it was interpreted [by employers] could be a barrier in itself.

> ‘They [employers] want to know what condition it is you’ve got, you know, intrusive you know, …. it seems that they think well if you tell me what you’ve got [impairment], and I will tell you how to deal with it sort of thing, which is the wrong way altogether.  We don’t need people to diagnose us, we know what we need, to adapt the place and make it work for us.’

A common thread was being ‘labelled’ as a ‘problem’ when initiating the need for RA, and being overly scrutinized and unfairly compared to others [who had no need for adjustments].

> ‘No-one wanted to know about making adjustments to enable me to do the job. I was considered to be a problem and not to be as quick as others. I was walking at the time [slowly and with difficulty], but it was upstairs as well so it was going up and down stairs 15 times a day [that was the problem], you know, just shattered me.’

The adjustment suggested by this participant was to locate him on the ground floor of the building, or to install a lift. The employer did not consider this to be a reasonable adjustment, as his colleagues worked on the first floor and the participant *could* use the stairs. No additional time was given to achieve work objectives, and comparison of his output was measured against able bodied colleagues. This resulted in his employment being terminated, on grounds of capacity.

### JCP services

Significantly only around half of the sample had had any contact or input from JCP advisors and DEA’s, the other half had no contact at all. The consistent view was that JCP staff were ‘only interested in their targets’ and in ‘pushing you in to low skilled work’, thereby reinforcing stereotypical views. Participants experienced advisors telling them to ‘lower your aspirations’, and exceptionally some discouraged participants, with what could be described as significant impairments, from trying work at all.

Some experienced being sent for interviews when they had been assured the building was accessible [wheelchair user] when it was not, and then being described as ‘difficult’ [by the advisor] for not turning up to the interview. This non challenging of employers was picked up by others, particularly when the employer was a two ticks holder.

> ‘ …. I was really surprised [at lack of RA] with …. [company] cos that’s one of the reasons why I applied to …. is the, they do have the two ticks logo …. and it’s yes we [the company] have this piece of paper [but don’t action the policy], and you know I had spoken to JCP about the problems we’re having, and they said just go and do something else, find a good employer. Surely if they’re not going to follow it up [two ticks symbol] and find out the truth, they shouldn’t have it [two ticks symbol].’

For some lack of information or knowledge of what help and support JCP and AtW could provide was the crux of the matter.

> ‘I have never had any contact from JCP about me and what help I could get to work.’

For others who had made contact with a DEA or IB advisor prior to starting work, no referral was made to AtW. At the interview some participants clearly still had unmet in work support needs. This [lack of referral] may be attributed to invisible impairment being equated to no need for AtW support, or in the case of complex impairments the DEA not having sufficient knowledge, and equally important, not involving the individual in assessing what support is needed. Some with hidden or complex support needs described it as demoralising to keep having to persist and try to prove their support needs, and also to be expected to know in advance of starting work exactly what support is needed.

> ‘…. they [DEA] don’t understand the complexity [of impairment] or difference that means it [support needs] is slightly different in each setting [work environment], and that’s been a big issue in itself, getting the sort of access to get the support that I need. And I am going to need specialised

> IT to support me in work.  I could do with it now for my work placements, but they won’t give it to me as the work placements are short term, and my regular work right now is voluntary, as I can’t get any paid …. experience that I need.  It all causes me problems, but they don’t see that.’

**Structural and Physical barriers**

Structural changes in the labour market (LM) were commonly regarding as barriers to work, with low paid, temporary jobs, and flexible [for the employer] work affording no security.  This heightened the risk factor, when considering a move from benefits to work.  Some had been in manufacturing industries that have declined or no longer exist [in the UK], and with the onset of impairment faced additional barriers of re-skilling.

> ‘I was sent on a rehabilitation and re-assessment course thing [at onset of impairment and subsequent job loss] by the DEA.  And when I came back the, in the area of …. there was no such work it had finished, light engineering had gone …. ’

Participants named a range of factors from rigid job designs; inflexible [for employees] hours; low rates of pay; to inaccessible toilets and buildings.

> ‘…. I had no direct access to [building] where I worked, I had to go through another building, that made it a longer more circuitous route.  They [employer] used to practise getting me out of the building [fire drill], but never bothered sorting getting me in it.  The toilets were just as bad – they [employers] work on the old [building regulations] guidelines [for access], they don’t ask me.  Now electric wheelchairs are made higher and wider than before and they [the employer] say – well its been checked [conforms with building regulations] and it’s fine, but it’s not for me.’

Rigid job designs or ‘the way things are done’ created a culture of the DP having to ‘fit in’ or be considered a problem.  This was particularly highlighted by the emphasis on competitiveness and output in the private and public sector.

> ‘I feel excluded from some jobs because of the speed of inputting [to computer] that is expected.  I can do it, but not as fast, as my [specialised] software slows you down.’

Multinationals or corporate business were viewed as interested purely in profits, and to thereby exclude DP.

> ‘I don’t think …. is where I will go.  Just because of the, it’s very much about profit and targets and things and it’s, I do enjoy that but that culture doesn’t accept difference, it [profit] takes precedence over everything else. It’s like what’s best for the big corporate’s.  You are disadvantaged already [impairment], and you’re disadvantaged again [competing].’

For some the rigidity of the job design created a barrier, when an often simple adjustment could remove it.

> ‘…. sort of like in the winter, trying to open the locks on the gates and you know, the internal locks as well, because my hands are particularly problematic in the winter [Rheumatoid Arthritis].’

This activity did not make up a key part of the job description held, but the rigidity of the job design and of the employer, posed a significant barrier to remain in work.

**Enablers**

The factors identified by participants may be grouped under four headings, namely; social capital; employers and support mechanisms; benefit system; stepping stones.

### Social Capital

Mirroring the findings captured thematically as barriers to work, access to education and gaining skills, were seen as key tools to work.  Personal development was seen to increase the opportunity of rewarding work [which participants aspired to], and in gaining work in general, as employers needs for skilled workers was seen to have increased.  Information Technology (IT) skills in particular were viewed as important both in accessing further information and education, and as a key skill necessary in most organisations.

> ‘The [IT] skills that I have, that I learned at Newlink, is how I got the job. They [employer] were pleased to get me, with the skills I had.’

Amassing skills and experience was also used as a compensation strategy to be better, more qualified, and have more skills [than others] in an attempt to deflect the negativity around impairment.

> ‘You feel you have to be better at it, be a bit more obsessive about getting it right.’

### Employers and Support

A recurrent theme was the pivotal role that employers have in whether DP are successful at gaining and staying in work.  The culture of the organisation, whether disability friendly and aware; critically having accessible buildings and toilets and essentially supportive employers, were key to successful employment.

> ‘With …. , they were very supportive, there was a lovely culture. You know very quickly what attitudes are, it’s almost like instinct, you can feel it. Everyone was an individual in the company, and it [company] had a lot to offer. So I needed a particular routine [for impairment], someone else needed flexibility for childcare. I wasn’t made to feel different.’

The culture or feel of the organisation affected whether or not it felt ‘safe’ to initiate adjustment needs and ask for support. This in turn led to increased opportunity to concentrate on the job, rather than the barriers, with consequential raised confidence and self esteem.

Organisations of disabled people as employers, were widely seen as examples of good practice, valuing skills and difference.

> ‘The reason I like working for Newlink is because nobody sees you as a disability, they don’t see the wheelchair, they see you and value you and that is the difference from when I was working in ….’

The most significant factor or difference highlighted about organisations of disabled people, compared to other employers, was the understanding of the impact of impairment on the individual.

> ‘…. having an understanding of the time it takes you to do things [physical disability] and the equipment you need. The biggest difference is I can get around, and in, the building, and also the educational barriers that people sometimes may not have the skills they should have because of their educational background. So I think I’ve felt more confident in this job than I’ve felt in a long time.’

Having accessible buildings was important, ‘it makes it possible’ [to work], and autonomy over how to do the job was needed by some, often equated with a professional or more senior role.  Employers who had disability awareness training for employees were seen as being generally supportive, and key to DP being accepted in the workplace.

Widespread use of strategies such as fitting in or appearing normal, were used by those with invisible impairment, with minimisation of impairment effects and compensation actions such as working harder or more hours, used by others. Exceptionally assertiveness was used, as was knowledge of the employers duties to make reasonable adjustment, both strategies however were considered risky, and used as a last resort.  Significantly, detailed knowledge of the DDA was at a low level in the study group.

And finally a universally needed support was flexibility in the number of hours worked, with all participants using part time work options [at some point] to increase the likelihood of remaining in work, with consequential reduced earning capacity.

**Benefit System**

Described as ‘essential’ is the help and support provided by AtW, this key policy initiative attracts bouquets and brick bats in equal measure.  When working optimally it transforms and removes barriers to employment created by inaccessible transport, inaccessible buildings [lift installation], provides support workers and essential equipment.

> ‘The biggest help is AtW.  Without a support worker, I wouldn’t be able to function and do the job.’

Exceptionally, the permitted work option was viewed very positively, but was largely not known about.

> ‘I thought the permitted earnings was a fantastic thing, and I think if they’d come out with something like permitted earnings sooner, I’d have gone straight for it.’
>
> (Unemployed and on IB 15 years)

DLA was commonly used to bypass inaccessible public transport, and used to support voluntary and remunerative work. Those in remunerative work using DLA for taxi’s to work, were largely unaware of AtW provision.

### Stepping Stones

Emphasised as very important were the gradual steps to work, often over a number of years, that enabled participation in employment. Voluntary work featured highly as both rewarding in itself, and as a route to gain skills in a chosen area. The ability to choose the area of work was used to gain experience or to try out that area of work, or capture skills for future work plans. Voluntary work also helped to, rebuild confidence and self esteem; to try out coping strategies; and to gain experience of what adjustments would be needed in a move to remunerative work.

> ‘I think the gradual steps are the most important to me, trying different voluntary work first gave me confidence to go and really give it [work] a good try. Yeah, the gradual steps getting back [to work], definitely.’

Participants also used education to gain qualifications needed for the particular job they aspired to.

### Work or Welfare

The division created by a capitalist economy was widely highlighted as creating further disadvantage for DP. Impairment is seen to be viewed as a problem by employers and out with the ‘normal’ structure of work, compounding the effects of impairment. All of the respondents cited remunerative work contributions spanning a wide range of occupations, and viewed work as a central and essential part of life. Equally cited were a wide range of external barriers which often blocked [their] access [to remunerative work]. Work was equated with being valued, contributing to society, and giving rewards, other than purely financial ones.

All respondents considered voluntary work to be important, and felt that society should accord voluntary work equal status to remunerative work. Some respondents were working voluntarily alongside paid colleagues, doing the same role, and requiring the same degree of professionalism.

> ‘I do voluntary work delivering health management courses for people who have a long term illness or disability. We are expected to be very professional and to present a professional image, to keep confidentiality and to handle difficult situations. All of these skills you acquire in the workplace. Without the volunteers working alongside the paid colleague, the courses would not run, as there are insufficient resources.’

A widely held view was that society would be unable to function without voluntary workers, and value [reward] should be based on the contribution made.

The factors that affected respondents choices and options of remunerative, voluntary work or both, were directly linked to the barriers they faced. Some respondents reported feelings of isolation, and of feeling outside of the capitalist economy. Voluntary work was viewed as a route to connecting with, and contributing to the society they were living in, but not necessarily a part of. Many reported feeling additional stigma, on top of that experienced by impairment, by being portrayed as dependent and unwilling to work, in essence being blamed for their exclusion from work.

In sum, this studies participants viewed work as an integral part of life, with many rewards, alongside financial ones.  For them work was considered to include voluntary and remunerative work in the public, private and third sector.  The respondents reported increased feelings of stigma associated with the welfare to work agenda, and perceived that the contribution they make [to society] is not recognised or valued.

# Chapter 6 – Conclusion

## 6.1 Introduction

This study aimed to add DPs account to the policy agenda around disability and work, by exploring the experiences and aspirations of DP in work. In particular it was hoped to discover what motivated DP to work, what barriers they experienced to work, and what they considered work meant for them in a society structured around the job role. The literature review identified a dichotomy of views relating to the economic exclusion of DP, in essence that DP are dependent and sick and have low aspirations to work, or they are oppressed and excluded from work.

This chapter will now review the findings in relation to the key areas identified in the literature review as relevant to the research questions. This will be followed by an explanation of the significance of the context of this research, and the implications for social policy.

## 6.2 Relationship of findings to the literature review

This study aimed to explore the basis of the dependency culture view by analysing what motivated DP to work. All of the participants in this study group may be considered as having impairments that have a significant daily impact, in essence satisfying the criteria within the DDA. Most had been fractured from the LM for considerable periods of time, and may hold certain similarities with what has been described as the caseload of long term IB recipients.

The literature review highlighted a range of theories around motivation and work, with a range of opinion between financial reasons and other non financial reward, such as social contact. For the participants of this study a number of factors were involved in the decision to work, with the main motivating factors to work emerging as, psychological factors of self worth and self esteem. Exceptionally financial reasons were the primary reason, with underlying or secondary psychological factors. For half of the respondents, financial considerations were not a factor, as for them there was no financial benefit to being in work. A number of participants accepted little or no financial reward to gain the other rewards associated with work, often by doing voluntary work.

The study participants also experienced physical access barriers, and discriminatory attitudinal barriers from employers. This impacted on their motivation and aspirations to work, with many participants reporting reduced motivation as a result. Motivation levels and the likelihood of remunerative work is represented as a continuum at Appendix 10.

The NDDP and PTW model of work first and targets puts an emphasis on a quantity approach to jobs. This study has shown that the participants were motivated by job satisfaction and high skilled jobs, creating a mismatch between policy intent and outcome, or in other words a gap in the strategic fit. Although this study is qualitative and the findings cannot be generalised to a wider population it is interesting to note that the participants were choosing to up skill themselves, to put them in a better position to target the primary sector jobs market. The governments activation policy for IB recipients emphasises that one third say they want to work. None of the participants in this study had been activated by JCP, and any AtW [adequate or not] or other help had been through their own knowledge or enquiry. This finding is consistent with the literature that AtW is not well published and is a lottery of provision. Some were in remunerative work with unmet needs that could put the job at risk, and others who aspired to work were unaware of what help or support was available. The focus of JCP activation is not necessarily being targeted at those DP who want to work, and this study suggests that distance from the LM is not an accurate measure. Information on JCP services and support [for example AtW] targeted at this group may help to improve their success rate of gaining and staying in work.

The literature review identified a range of barriers to work for DP, with an often complex interplay of the factors. One of the major issues to emerge in this study was the complexity of the benefit rules, that may act as a disincentive to work, for those in receipt of means tested IS for example, reflecting the findings in the literature review. DP in this study emphasised the need for many steps to be taken in a gradual return to the LM, and the majority need to work part time. Those most likely to be in receipt of IS are those who have done little or no work [furthest from the LM], are householders, or have children. Essentially those at greatest risk of poverty, have the strictest benefit rules, making those gradual steps unlikely, and at any rate can only increase their income by £20.00, by working up to 15 hours. The likelihood of low paid work with the work first approach also means many are no better off in work. This acts as a disincentive to try work, as does the fear of benefit review.

The majority of the study group reported the need to work part time [for impairment and barrier related reasons], thereby reducing their earning capacity. There is no specific benefit aimed at those who have a reduced earnings capacity of this nature. [Supported employment provision may provide a useful comparison here, as it supports DP whose output is reduced, not necessarily the amount of hours worked.] Providing the hours the individual is able to work does not fall below 16, tax credits may be claimed. Unless the individual is in a high earnings bracket and does not qualify for TC, the risk of in work poverty is heightened. The profile of substantial barriers to work experienced by DP in this study, and as found in the literature review suggest that high earnings are unlikely for the majority of the participants. This is an area that needs further research, as is the fact that for some paid work is not an option.

Organisations of DP were highlighted as good employers [reflecting the findings in the literature] and provide quality job opportunities for DP. Along with many other organisations of DP, Newlink is facing funding issues (Disability Now, July 2006), with the possibility of job losses. There are a range of factors that impact on this crisis of funding, for example the closure of day centres and the mainstream agenda. The impact of, and perverse outcomes of cross cutting government agenda's is an area needing further research.

And finally particular areas of work for example the medical profession are resistant to DP, this finding is reflecting in the literature review, and needs further research.

## 6.3 Conclusion

The political ideology [in the UK] underpinning the Welfare to Work agenda, has resulted in social policy aims being tailored to the market agenda. This government, whose stated policy aim is Opportunity for All, aims to deliver welfare ends through market means, with inevitable incompatibilities. By combining the economic case for engaging with IB recipients [and a stated one third of whom say they want to work], with the civil rights movement agenda for economic inclusion, the outcome is the work first approach.

Initially NDDP [with a work first emphasis] was a voluntary programme, however PTW [whose main programme is NDDP] is now rolling out nationally with mandatory participation and increased conditionality. NDDP is currently about matching people's skills with those of prospective employers, with an emphasis on targets and outcomes. DP are disproportionately low skilled due to a combination of segregated education and low aspirations of others, whilst the LM has polarised to high skilled work with high rewards, or low skilled, casual, low paid work. The result is high rates of poverty and social exclusion for DP in receipt of welfare, or the likelihood of in work poverty with low paid work. The governments approach is based on a dependency culture view, increased conditionality and mandatory participation in PTW, clearly signalling the direction of travel.

This study has shown that DP are motivated to work by the same range of factors as non disabled people.  However, they face significant barriers at every turn and at every level, and despite their obvious resilience, many do not survive in competitive employment due to discriminatory and other barriers.  That DP are capable of a wide range of high skilled work is evidenced here.  In a capitalist economy, simple supply side measures are not delivering either the stated policy objectives, nor DP's aspirations to work.

The participants of this study had views on what more needs to be done to ensure their economic inclusion.  These views are listed at Appendix 12.

But perhaps it is fitting to end this report with the words of one of the participants.

> 'DP have ambitions [to work] just like everyone else, and they can be extremely good and successful at what they do.  Perhaps the issues aren't so great as people [employers and others] think they are.  Why can't they just let us try, let us join in [work].'

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## END NOTES

1. DDA (1995) a landmark piece of legislation giving the first rights for disabled people not to be discriminated against. Despite that it has achieved very little and the act is considered weak by Disability Rights activists. The DDA made it illegal to discriminate against disabled people 'in connection with employment, the provision of goods, facilities and services or the disposal or management of premises.' Individuals [rather than Crown Prosecution] must bring cases to enforce their rights.

2. Poverty
   60% of median income is the measure used for practical [comparative] purposes, however, poverty also includes exclusion from public services, and from participation in [societies] an acceptable way of modern life, and thereby participating in the prosperity of that society. This means that goods that may have been considered a luxury before, i.e. a washing machine, become a necessity. Also the concept of poverty may be short term or temporary when due to job loss, or long term and enduring poverty and deprivation, due to illness or disability [resulting in fracture from the labour market and dependence on low rates of benefit] or poverty and exclusion resulting from lack of access to leisure amenities through lack of physical access, or as a result of earlier segregation [in education for example] may mean the disabled person is stigmatised and has no social group to interact with.

3. Social exclusion is shorthand label for what can happen when individuals or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime environments, bad health and family breakdown. (Social Exclusion Unit).

4. The New Deals represent a radical paradigm shift from welfare to workfare, from Keynesianism to competition state with conditional welfare benefits. The 'problem' is to reduce dependency on welfare, increase citizen responsibility and state competitiveness in a global market, whilst selling the ideal as the answer to social exclusion.

5. NDDP – piloted in 1999 and implemented in 2001. The New Deal for Disabled People (NDDP) is a voluntary programme that aims to help people on incapacity benefits move into sustained employment. NDDP is delivered by a national network of local Job Brokers comprising public private and voluntary sector providers of varying types and level of work-focused support and assistance. The programme offers four options including subsidised employment, education and skills training, whilst focusing on work first.

6. PTWP
Introduced in October 2003 to Jobcentre Plus sites on a pilot basis to provide more skilled advice and help to return to work for people coming on to Incapacity Benefit, by specialist Incapacity Benefit Personal Advisors, with new mandatory work focused interviews (to initiate the claim) combined with joined up services with key stakeholders, in particular GPs and employers. The provision is still on an extended pilot basis and covers around one third of the country at the present time, concentrated in areas of highest registration of IB clients of working age, and its success has contributed to the modest increase in employment levels of disabled people.

7. Supply side – The side of an economy which determines how many goods are supplied at any given price. In a competition state the government ensures a ready supply of labour with an emphasis on conditional welfare.

8. Definitions of disability

The two main models are:

The Medical Model – this sees disability as an illness, and disabled people as patients in need of a cure so that they can fit in to 'normal' society. The emphasis is on the condition rather than the person, and therefore the measure against an able bodied 'norm' marks the disabled person as 'deficit' and in need of adjustments, for example, DDA 1995.
The Social Model – this recognises disabled people as equals who are faced with very unequal situations – for example society's attitudes. The emphasis is on society's responsibilities and need to change attitudes, rather than the disabled person's problem. Disabled activists see disability as the product of definition and practices that exclude individuals who are seen to deviate from the accepted 'norm'. The state is seen as being preoccupied with social order, segregating individuals in terms of perceived abilities, for example to meet the dictat of the work place. The welfare state regulates exclusions, with the 'sick note' gaining the individual an exemption of the social obligation to work.

The Social Model suggests a strategy of barrier removal and education to remove the prejudices and discrimination inherent in this socially constructed 'normal' society, with a goal of social and economic inclusion, whilst celebrating difference.

Barnes and Mercer (2003)

In essence – that disability is the construct of social structures and organisation. Critics of this model would challenge its failure to address all of the factors shaping the production of disability, just as feminists were criticised for limiting the experience to white middle class western women.

The WHO ICIDH definition was revised in 2001 to reflect more positive language, whilst retaining the underpinning medical model basis. The WHO ICIDH is favoured by medical sociologists who argue that the social model is over socialised and does not take adequate account of the restriction in activities caused by chronic illness and disease.

Disability theorists also reject the labelling or medical model approach of the World Health Organisations International Classification of Impairments, Disabilities and Handicaps (WHO, ICIDH 1980), as disability and the disadvantage arising from it, is seen as a consequence of the impairment or chronic illness (Barnes & Mercer, 2003).

9. Disabled people's movement – emerged in the 1970s founded on the work of Hunt and UPIAS, and fractured from the Disability Income Group (single issue), formed the basis of BCODP (British Council of Disabled People, now rename the United Kingdom Disabled People's Council).

10. ODI – Office for Disability Issues. The focal point within government charged with co-ordinating disability policy across Whitehall departments, and to take forward the Life Chances Report.

11. Equality 2025 – an advisory body made up of disabled people enabling disabled people to communicate directly with government.

12. NewLink Mission statement:
NewLink's mission is to support personal development by providing accessible training, work placement, and employment opportunities.

Throughout its twenty-two year history, NewLink has had to accommodate trends in funding initiatives.

Initially the organisation was funded by the University of Nottingham's Adult Education programme and was non vocational. Building on the success of the initial training courses, NewLink achieved funding from the European Social Fund (Objective 3), and Community Initiatives such as HORIZON, EUROFORM, HELIOS, PETRA, to deliver vocational training programmes for disabled and long-term unemployed people. Following this, we enjoyed the benefit of a large grant from the National Lottery. In 1995, the organisation negotiated a franchise contract with the Learning and Skills Council, through City College Coventry, for the majority of its IT training provision. It provided a comprehensive range of educational and training opportunities in and through Information Technology at various different levels, ranging from non-vocational education for those with learning difficulties, through introductory courses in the use of computers, courses for those with visual impairment, vocational training courses leading to National OCR and NVQ qualifications, including Adult Literacy and Numeracy. For those unable to access the NewLink training centres, home-based training was available, with one-to-one tutor support and the use of distance learning packages.

Computer training rooms were established in nine Social Services centres, in partnership with County and City Councils in Lincolnshire, Nottinghamshire and Derbyshire. In four of these centres NewLink established workshops, run and managed by disabled people, providing Desktop publishing services to small local businesses and other charitable organisations. One of the many barriers to moving into employment for disabled people is the lack of opportunity for work training or work experience. Run as businesses, these workshops provided work experience and work training to disabled people in fully accessible premises, giving the opportunity to gain National Vocational Qualifications (NVQs) in IT and Business Administration, and providing a springboard into employment.

Our courses offer Best Value, in terms of tutor-learner ratio and facilities to support additional special needs.

In the period 1985-2005, over 5000 disabled people enjoyed good quality ICT training and education, in small friendly classes, in an accessible environment. NewLink developed a policy of offering employment opportunities to its graduates and to this end about 80 people have had contracts as tutors, workshop managers, class room assistance and in administration. Others have taken up volunteering opportunities within the organisation or been successful in gaining employment elsewhere.

In 2003, NewLink became the first Social Firm to be established in the East Midlands. A Social Firm is a market-led enterprise set up specifically to create employment opportunities for disabled people.

Also see Appendix 11.

13. Globalisation incorporates increased internationalism, economic changes reflecting changes in patterns of production, increased and instant communications, increased monetary flow with little or no national boundaries or barriers. It also introduces the possibility of Multi National corporations to hold governments to ransom by their ability to shift production [and hence employment] rapidly, to other countries, to enhance profits, resulting in a disempowering of the [nation] state.

14. The post war [1945] paradigm shift to a social democratic welfare state system with extensive state intervention, was based around an assumption of full employment with a male [able bodied] breadwinner, and was therefore detrimental to the prospects of disabled people, as they had to rely on a residual means tested benefit with consequential stigma (Hills

et al, 1994.1). The rejection of Keynesianism in the 1980's marked a radical paradigm shift and return to individualism in favour of a non-interventionist economic approach: lower tax burdens: privatisation of public services and supply-sideism.

15. Inclusion has a powerful dimension of belonging and participation.

16. Educational handicap – specified by Walker to mean that the young person had either been classified or ascertained as needing special educational help at age 16; or had been receiving such help, though not formally classified; or were thought to have needed special help. The specification included those with a physical handicap, requiring special education treatment, and those 'retarded' by irregular attendance or other social factors.

17. National Minimum Wage.

18. Tax Credits – an in work benefit to supplement low earnings, withdrawn on a 'sliding scale' as earnings increase.

19. Permitted Work.
Incentives within the benefit system to encourage IB recipients to try work, include the provision of unlimited voluntary work, or permitted work [which replaced the more restrictive therapeutic work that required medical input]. The rules covering remuneration from permitted work [PW] are different for those in receipt of contributory IB, and those in receipt of means tested Income Support paid as a top up to IB or because the recipient has insufficient national insurance contributions.

20. SENDA – Special Education Needs and Disability Act.

21. ICT's – Information and Communication Technology

22. Royal National Institute for the Blind.

23. Access to Work – a little known government programme to support DP in work. The main criticisms are its lack of profile, including with JCP staff, and a lottery of provision.

## Appendix 1

## Policy Initiatives aimed at DP and work

Reproduced and adapted from Benefits Number43 -Volume 13 • Issue 2

Box I: Disability milestones and reforms 1997-2005

1997
- BIP reviews of DLA entitlement continue
- £197 million windfall levy allocated to NDDP
- Disability Rights Task Force on civil rights

1998
- Work incentives improved (one-year linking rule, abolition of 16-hour limit on voluntary work)
- NDDP Personal Adviser Service and innovative employment schemes piloted
- Welfare reform proposals published (renaming the IB all-work test, work focused interviews, changing contributory conditions and offsetting pension income, ending SDA for new claims, lowering the DLA mobility component age bar for children, ending 'life' awards, 'disability income guarantee' for severely disabled people)

1999
- BIP replaced by periodic enquiry
- DWA replaced by DPTC
- Welfare Reform Act passed
- DDA further rights of access implemented and Task Force recommendations published
- Personal Adviser Service introduced for disabled people living in ONE areas

2000
- Work incentives pilots and WFIs mandatory in ONE areas
- Disability Rights Commission set up

2001
- Supported employment programme replaced by WORKSTEP, with incentives for progression
- NDDP national extension (Job Brokers)
- Department of Health publishes Learning Disability strategy ( *Valuing People)*
- New DWP, agencies of JC+ and Disability and Carers Service
- Mandatory WFI's in JC+ Pathfinder offices and most IB recipients reviewed every three to five years
- Extension of Direct Payments in lieu of community care services
- Special Educational Needs and Disability Act, extending DDA into education

2002
- 'Therapeutic' work replaced by permitted work
- Independent Living Fund means test: earnings ignored and capital limit raised
- JC+ begins roll-out: WFI's and the PCA process brought forward by 10 weeks
- 'Pathways' proposals: WFI's, employment 'choices', condition management programmes, Return To Work Credit

2003
- Job Retention and Rehabilitation pilots start
- Pathways pilots start

## Appendix 1 (continued)

- New tax credits introduced, including disability elements
- British Sign Language officially recognised
- Disability Bill to extend the DDA and introduce a public sector duty to promote equality

2004

- Pathways -extended to more areas, a wider group (with added financial incentive), more resources for NDDP
- DDA extended, eg, to small employers and final rights of access introduced
- Social Exclusion Unit publishes report on mental health
- DWP publishes strategy for Building on New Deal and Framework for Vocational Rehabilitation

2005

- Prime Minister's Strategy Unit publishes report on the life chances of disabled people
- DWP publishes Five Year Strategy
- Improved linking rules announced in 2005 Budget

## Appendix 2

## The Competition State, Disability, Work and Poverty

The neo-liberal workfare regime of the 1980s and 1990s of economic policy first and the [free] market agenda, witnessed social policies whose covert aim seemed to be to further separate out individuals in terms of abilities to compete in the workplace, with conditional [and increasingly inequitable] welfare for those regulated out. This period has been characterised as a competition state by Evans and Cerny (2003),with the objective to mobilise all those who can into [often low paid] work in a competitive global economy.

The polity of the New Labour government [from 1997] has seemingly sought to ameliorate or redirect the neo-liberal approach so that economic and social policies appear to support each other, or as Evans and Cerny (2003.30) put it 'taking the hard edges off capitalism without losing it's wealth creating drive'. There has been no u-turn or about turn however, and the increasing conditionality of welfare [or workfare] is evident in, for example, 'as support is increased, so will the level of conditionality for claimants' (DWP, 2006).

In addition the New Right neo liberal policies of the 1980s restricted benefit increases in relation to prices, rather than earnings (Townsend 1993.223). This situation remains today for working age benefit recipients without children, contributing to relative poverty for this group (Palmer et al, 2006.16).

Disabled people have been first structurally excluded [from the period of industrial revolution] from the labour market, and now face a second exclusion by what has been characterised as an information society, whose currency is knowledge and skills. This exclusion is compounded by the right to work replaced by the [citizens] *responsibility* or duty to work, without equal measures to address the [often multiple] sources of disadvantage, or consideration of the reality of in work poverty for DP who may be pushed in to low skilled, low paid work (Preston, 2006.5).

## Appendix 3

## Examples of the costs of disability and poverty in low paid work

Table 26 National average wage model: weekly income of employed disabled people compared with disabled person budget standards (to nearest £)

| Total income per week (£s) | | Disabled person budget standard | Income after costs per week |
|---|---|---|---|
| High-medium needs | 451 | 533 | -82 |
| Low-medium needs | 351 | 345 | +6 |

Components of income

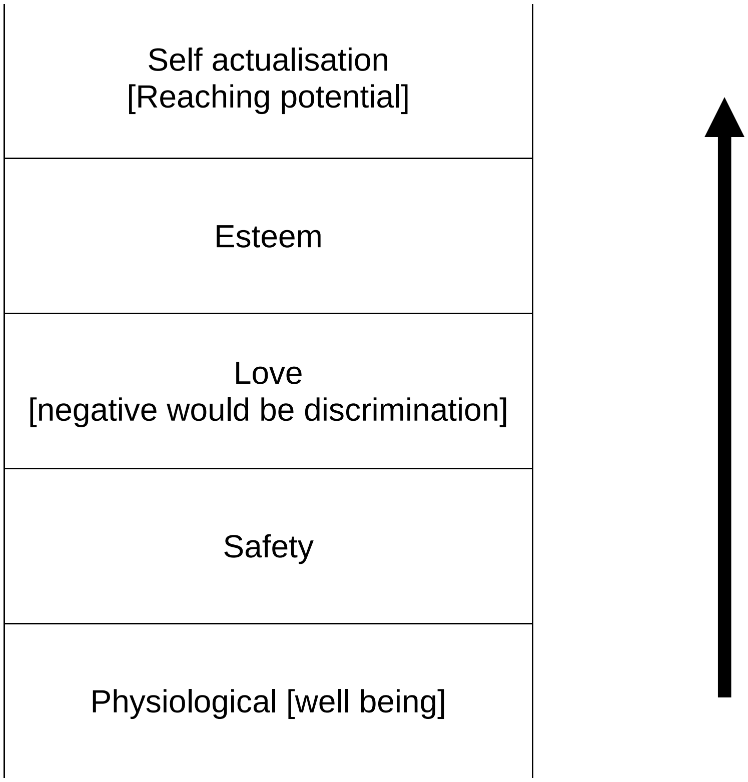
| | |
|---|---|
| High-medium | Net wage + DLA (higher-rate care and mobility) |
| Low-medium | Net wage |

The example shows that the income of a person with low to medium needs receiving the national average wage would cover his/her costs. (If personal assistance costs were met via public services). However for a person with high-medium needs an income consisting of the average wage and DLA would still not meet their needs.

Reproduced and adapted from Smith et al (2004.80)

## Appendix 4

### Maslow's theory of a hierarchy of needs.



Each level may be view as stepping up one rung of the ladder when satisfied. Exceptionally, individuals may choose to bypass one level to fulfil higher more pressing needs. Although originally not developed for work motivation theory has been widely used to explain human motivation. The motivating factors are toward the top of the ladder.

Adapted from Maslow (1943).

## Appendix 5

### Invitation to Interview

**University of York**

**Department of**
**Social Policy and**
**Social Work**
Heslington, York YO10 5DD
Telephone (01904) 433000
Direct Telephone (01904)
Facsmilie (01904) 321270
http://www.york.ac.uk/depts/spsw/

Dear

I am currently undertaking independent research on the experiences of disabled people and work, for my Masters Degree dissertation at the University of York.

The focus of the dissertation is to understand disabled peoples experiences and aspirations in all aspects of considering or entering work, and any barriers you consider may make that difficult to achieve. I am interested in what you have to say, whatever your circumstances and thoughts are about working, and your views about what it means to you. It is intended that the findings from this research will be made available through Jobcentre Plus.

Everyone who is enrolled with Newlink is being approached to see if they would like to be involved. Participation is entirely voluntary and if you do decide to be involved the services and benefits you receive will not be affected in any way. All answers will be treated **in strict confidence** and in accordance with the **Data Protection Act.** Findings will be presented in a way that will not make it possible to identify any individual who has taken part. In other words I will **not** use peoples names in any way only the views expressed.

Participating in the project will involve a one to one interview with me at Newlink premises or another location of your choice. I can help you to take part by paying your transport costs for example. It is intended that interviews will take place during September 2006, and will last approximately one hour.

If you wish to take part please return the enclosed reply slip to me by the 25 August 2006 in the envelope provided, or email me at fck500@york.ac.uk. If you wish to ask any questions please call me on 07733 002183.

I hope you will be able to take part in this important study and I look forward to hearing from you. Once again, please be assured your participation is entirely voluntary and **strictly confidential.**

Yours sincerely,

Mrs F M Chapman-King

IF YOU REQUIRE THIS INFORMATION IN LARGER PRINT, ON AUDIO TAPE, IN BRAILLE OR ANOTHER FORMAT PLEASE CONTACT ME ON 07733 002183.

**REPLY SLIP**

I will / will not be willing to take part in your research.

I am / am not available to be interviewed during September.

Signed: ………………………………………………..

Print Name: …...…………………………………………

# Appendix 6

## Personal details thematic chart

| ***Personal Details*** | ***1.1*** | ***1.2*** | ***1.3*** | ***1.4*** | ***1.5*** | ***1.6*** | ***1.7*** |
|---|---|---|---|---|---|---|---|
| ***Ref No*** | ***Gender*** | ***Age*** | ***Household*** | ***Impairment*** | ***Current Employment*** | ***Work History*** | ***Educational Qualifications*** |
| A1 | Male | 20 | Single. Lives with parents. Mother is a SEN teacher. Father engineer. | Neurological condition. | Private Sector – pharmacy dispensing 4hrs on voluntary unpaid basis.<br>Voluntary sector min 4hrs per week – swimming instructor, student ambassador, work with disadvantaged young people. | 1 week school placement with Access to Work team – age 16. Various voluntary work, commenced 16yrs and continues.<br>Private sector employment as trainee pharmacist in major pharmacy chain 05.<br>Private sector employment in industrial pharmaceutical industry past university 06.<br>NHS employment 07 secured. Employer of support workers. | A Level – currently doing MA in pharmacy. Mainstream, segregated & private education. |
| H2 | Female | 45 | Partner, two children age 12 & 18. Partner works. | Neurological condition. | Public Sector – learning assistant further education college. Full time. | Private sector clerical work, office admin, computer input, 5 yrs.<br>Home worker supervisor – positive recruitment DP (local authority). National Trust recruitment officer. Volunteer tutor. Teaching assistant, Tutor and general administration. Short periods (less than 1 yr) unemployment between jobs. | Educated to MA degree level. Educated in mainstream education. No work experience until graduated. Adult education teaching certificate. |
| C3 | Male | 55 | Single, lives alone. | Visually impaired. | Third sector, part time 10 hrs per week on a voluntary basis.<br>Associate tutor and admin tasks | Private sector – baker for 20 yrs from school leaving age until progressive sight loss enforced early retirement. Not redeployed. Unemployed 10 yrs. | Mainstream education. No formal school leaving qualifications. IT course, NVQ Level 2, 3. Adult education teaching certificate. |
| J4 | Female | 40 | Lives with partner, partner employed | Rheumatoid arthritis – started in 20s. Currently stable but is progressive.<br>Impairments not visible. | Public sector – full time. Key reflections manager (Art Gallery). | Industrial machinist for 8½ years from school leaving until onset of Rheumatoid Arthritis. Unemployed 10 yrs. Associate tutor (voluntary). Learn Direct tutor (voluntary). Volunteer worker at Art Gallery. Heritage Assistant (part time) (Public Sector. | Mainstream education, few GCSE's. Returned to education after contact with Newlink, (IT course), completed adult education teaching certificate. B of A degree, BSC (IT) and MA. |
| M5 | Male | 55 | Married, one teenage child. Wife has MS and is unofficial carer. | Due to accident. Wheelchair user. Has day and night care needs. | Third sector – workshop manager, course co-ordinator, full time. Third sector – voluntary work with groups of disabled people. | Mechanic from school leaving age until accident. Unemployed 20 yrs. Then various voluntary work, associate tutor. Now employs own care workers. | Mainstream education, no formal leaving qualifications. Returned to education, various correspondence courses, accounting, book-keeping, Law course at night school. City & Guilds (IT). Various IT courses. Adult education teaching certificate. |
| I6 | Male | 44 | Married, wife works. | Nerve damage in spine. Neurological condition – similar symptoms to stable MS. Has stable mobility difficulties uses sticks to aid mobility. | Insurance Referencing firm in private sector – assesses credit rating and references for prospective private housing tenants, using IT and phone contact. Full time, plus overtime. | Apprentice jockey. Shop Assistant. Various manual jobs in manufacturing. Self employed painter and decorator. Unemployed 15 yrs due to onset of impairment, lost job. Volunteer tutor. Associate tutor – part time. | Mainstream education – no formal school leaving qualifications. Various IT courses. Adult education teaching certificate. |

## Appendix 6 (continued)

| ***Personal Details*** | ***1.1*** | ***1.2*** | ***1.3*** | ***1.4*** | ***1.5*** | ***1.6*** | ***1.7*** |
|---|---|---|---|---|---|---|---|
| ***Ref No*** | ***Gender*** | ***Age*** | ***Household*** | ***Impairment*** | ***Current Employment*** | ***Work History*** | ***Educational Qualifications*** |
| K7 | Male | 43 | Married, wife, employed. | Mobility difficulties. Wheelchair user. | Third sector, tutor IT skills, 15 hrs per week. | Job creation scheme 1 yr. Furniture finisher, unemployed 8 yrs. Temp job in employment service – 1 yr. Disability Access job – local authority, temporary. County council careers service clerical work – 1 yr temp. Unemployed, several years, voluntary – associate tutor. | Segregated education – no formal leaving qualifications. Various trainings schemes with YTS. Various IT courses. Teaching certificate. |
| S8 | Female | 52 | Married, 2 grown up children. Husband employed. | Parkinsons disease (late adult onset 4yrs ago). Degenerative condition. | Private – subcontracted technical consultant for Access to Work, spasmodic, occasional employment. Private – physiotherapy occasional private practice cover. Voluntary – Health management courses 1 day per week = 6hrs. | Qualified as physiotherapist in 1976. Various jobs in NHS & private sector for 23 yrs. Moved to occupational health role in major blue chip company – 4 yrs (full time). Early retirement 03 – health reasons, at onset of impairment. | Mainstream education – qualified to degree level. Member Chartered Society of Physiotherapy. |
| S9 | Female | 34 | Single, lives alone. | Muscular Dystrophy. | Third sector, associate tutor, voluntary – 3hrs per week. | Accounts junior (temp) – local authority. Clerical worker – police (temp). Various other temporary clerical jobs primarily in public sector. U/E 7 yrs. | Mainstream education – GCSE level qualifications. NVQ level 2. Various IT courses, teaching certificate. |
| J10 | Female | 49 | Married, husband does not work. | Mytonic Dystrophy, rheumatism. Diagnosed with age 23. | Third sector, voluntary work various organisations. Hrs variable approx 13 hrs per week, dependant on impairment. | Office work – shorthand & typing. Shop assistant. Mothers helper. Nurse – left job when diagnosed with Mytonic Dystrophy. Unemployed 15 yrs. Associate tutor voluntary. | Mainstream education – no formal leaving qualifications. Course in shorthand & typing at Further Ed college. Various IT courses & NVQ level 2. Teaching certificate. |
| G11 | Female | 51 | Married, two children, one still dependant. Husband is her full time carer. | Spina Bifida – latterly a wheelchair use. Mental Health impairment, diagnosed age 37. | Third sector, associate tutor/admin tasks.<br>8 hrs week, voluntary. | Shop assistant – various. Domestic. Pub landlady. Money collector.<br>Diagnosed Spina Bifida. Unemployed 10 yrs, Welfare Rights Advisor, voluntary. | Mainstream and segregated mixed. Mainstream education – no formal leaving qualifications. Various IT courses & NVQ level 2. Teaching certificate. |
| T12 | Female | 39 | Single, lives with mother who is pensioner. | Multiple Sclerosis. Affects nervous system and is progressive. Depressive episodes. | Third sector, associate tutor 3 hrs per week. CAB advisor 5 hrs per week. | Waitress 11 yrs. Lost job due to onset of MS - couldn't do tasks. No adjustments. Unemployed 8 yrs. | Mainstream and segregated mixed. Mainstream education – no formal leaving qualifications. Various IT courses & NVQ level 2. Teaching certificate. |

**Appendix 7**

## DISABILITY AND WORK: THE EXPERIENCE AND ASPIRATIONS OF DISABLED PEOPLE

## TOPIC GUIDE

OBJECTIVES:

1. To add disabled peoples account to the current policy agenda of disability and work, by exploring the experiences and aspirations of disabled people in work.

2. To understand the motivating factors to work, and what work means to DP.

3. To consider the interaction of impairment and the work environment/structure, by identifying the barriers, enablers and strategies used for gaining and staying in work.

4. To consider the views of DP as to what more needs to be done to achieve economic inclusion.

### 1. INTRODUCTION

Introduce self, why doing research, personal interest as a disabled person in work, my role in Newlink, and a professional interest as I work for Jobcentre Plus. Therefore research may be of interest to DWP. This research is primarily being done as part of MA at York.

Explain purpose of research: Objectives above – to find out about the aspirations and experiences of disabled people and work.

Explain the issues which will be included in the discussion. Will last around 1 hour, need for breaks etc?

Reassure confidentiality, names will not be used in any way in the report of findings. Newlink and Jobcentre Plus do not know who has taken part and will not affect benefits in any way. Names will not be linked with the results or mentioned in the report, the results will be presented so that no one can be identified. Request permission to use tape recorder.

Emphasise that they may decline to answer any questions, and exit at any time.

Any questions, concerns etc?

Pay fares as appropriate.

2. I want to ensure that I have a varied sample for my research, and would like to ask some background questions.

- Are you single, married, living as a couple?
- Does anyone else live in your household with you (ie children)
- Are you the householder
- May I ask your age?

## 3. EXPERIENCES OF WORK

### 3.1 Employment details [and benefit history if applicable]

- Do you work? What does work mean to you (full time, part time, paid, unpaid, voluntary)
- Type of job, hours, employment dates, duration previous work.
- In work benefit/tax credit.
- Suitability of job, under/over utilised skills or abilities, attitude of other employees – job satisfaction, financial, hours, positive/negative.
- Changes in job since began (hours, pay tenure, responsibilities, aid/adaptions).

- Perception of job stability/aspirations for progression opportunities, position now [ie junior or senior position, temporary, permanent, stepping-stone].
- Reflection on job(s), (probe for both positive and negative aspects emplore, status, financial, self esteem, social contact, gaining experience, work environment, attitudes, pay/benefit.

### 3.2 Job entry

- How got job – factors that contributed to getting job – help from Jobcentre Plus, DEA or Job Broker/Access to Work/job coach, other, none.
- Role of any financial incentive/support (Job Grant/Tax Credit, benefit system, ATW.
- Did you declare a disability prior to job interview? Impact? – positive, neutral, negative.

### 4. Motivation

- I am trying to find out what motivates DP to work.
- What are your reasons for working
  Explore: financial, social, self esteem, participating in society, realising a goal, workfare policies.
- Aspirations or plans about work?
  Career move, voluntary to paid work or other work. Other. No aspirations …….

### 5. In work Enablers and Barriers

- Any work related difficulties experienced after entering employment (what, how resolved/unresolved). How did that make you feel? (Powerless, valued self esteem……).
- Kind of help/support needed (prompts: time learning the job, adjusting to work, adjustments to job role, peer/mentor support, someone to talk through issues with other than line manager, solving practical difficulties ie car

parking, help with benefit/tax credits, other guidance, financial etc), disability awareness for co-workers/manager.

- When needs arose (eg, at start, throughout, after x weeks/months).
- Feel secure/not secure to voice needs/seek help, have knowledge of whom to approach.
- Receiving in-work support – from whom (HR, TU, JC+/DEA, have knowledge of DDA/DRC, other agencies, family, workplace, peer support).
- Further prompt: Barriers/Enablers.

| BARRIERS: | ENABLERS: |
|---|---|
| • Hours too long/short/rigid<br>• Temporary/insecure work<br>• Negative/discriminatory attitudes/lack of understanding of disabling barriers<br>• Poor access to building/IT/toilets/other amenities<br>• Assumptions made – Disability = ineffective/sick<br>• Medical model<br>• Poor/lower rate of pay than other workers<br>• Low skilled menial work<br>• Inflexible structure of job<br>• Poor educational qualifications/skills<br>• Low self esteem<br>• Skills/abilities not full utilised/rewarded.<br>• Diversity not valued.<br>• Lack of DDA awareness<br>What (enabler is most beneficial/what | • Flexible hours/attendance<br>• Stable, good condition, equal pay structure<br>• Disability aware – culture of respecting difference<br>• Knowledge of DDA/staff/managers/HR<br>• Mandatory Equality Training.<br>• R/A made promptly<br>• Level playing filed on progression/promotion<br>• Accessible buildings?IT<br>• Social Model<br>• Autonomy of work organisation<br>• Supportive work environment<br>• On job training/career structure<br>• ATW (Access to work)/NDDF<br>• Coping strategies ie minimisation; compensation, openness, avoidance, fitting |

| | |
|---|---|
| more is needed?<br>• ATW not available<br>• Benefit rules/system<br>• Have the barriers changed over time/employer/DDA<br>• Discrimination/bullying/harassment<br>• Excluded from some occupations | in/appearing normal.<br>• Have enablers/strategies changed over time, or employer or DDA. |

## 6. IMPAIRMENT/DISABILITY

- Do you consider that you have an impairment or disability?  What is the nature [and duration] of your impairment?
- Are you familiar with the medical and social model of disability?
- Does your impairment have an impact on your daily routine at work. [What, how]
- Does your work environment impact on your job role [What/how affected]
- Is your work environment suitable for your needs. [Flexible, adapted, disability aware].

## 7. CLOSE

- Finally is there anything you would like to add in relation to anything we have discussed today?
- If you later feel you need any help or advice about any of the issues covered today you may find it helpful to contact DRC, Chief Ex Newlink, DEA, JCP or call me and I will try to direct you to other sources of advice/help.  (Give out contact details sheet and optional leaflet DHC1 JP)

REASSURE OF CONFIDENTIALITY, THANK PARTICIPANT AND CLOSE

## Appendix 8 – Conceptual Index

### 1. Personal details

1.1 Gender
1.2 Age
1.3 Household
1.4 Impairment
1.5 Current employment status
1.6 Other

### 2. Motivation/Aspirations

2.1 Financial reasons
2.2 Psychological reasons
2.3 Social contact
2.4 Stepping stone
2.5 Aspirations for other work
2.6 Other

### 3. Work or Welfare

3.1 Competition or Contribution
3.2 Routes to work
3.3. Activated?
3.4 Other (Value of Work)

### 4. Barriers

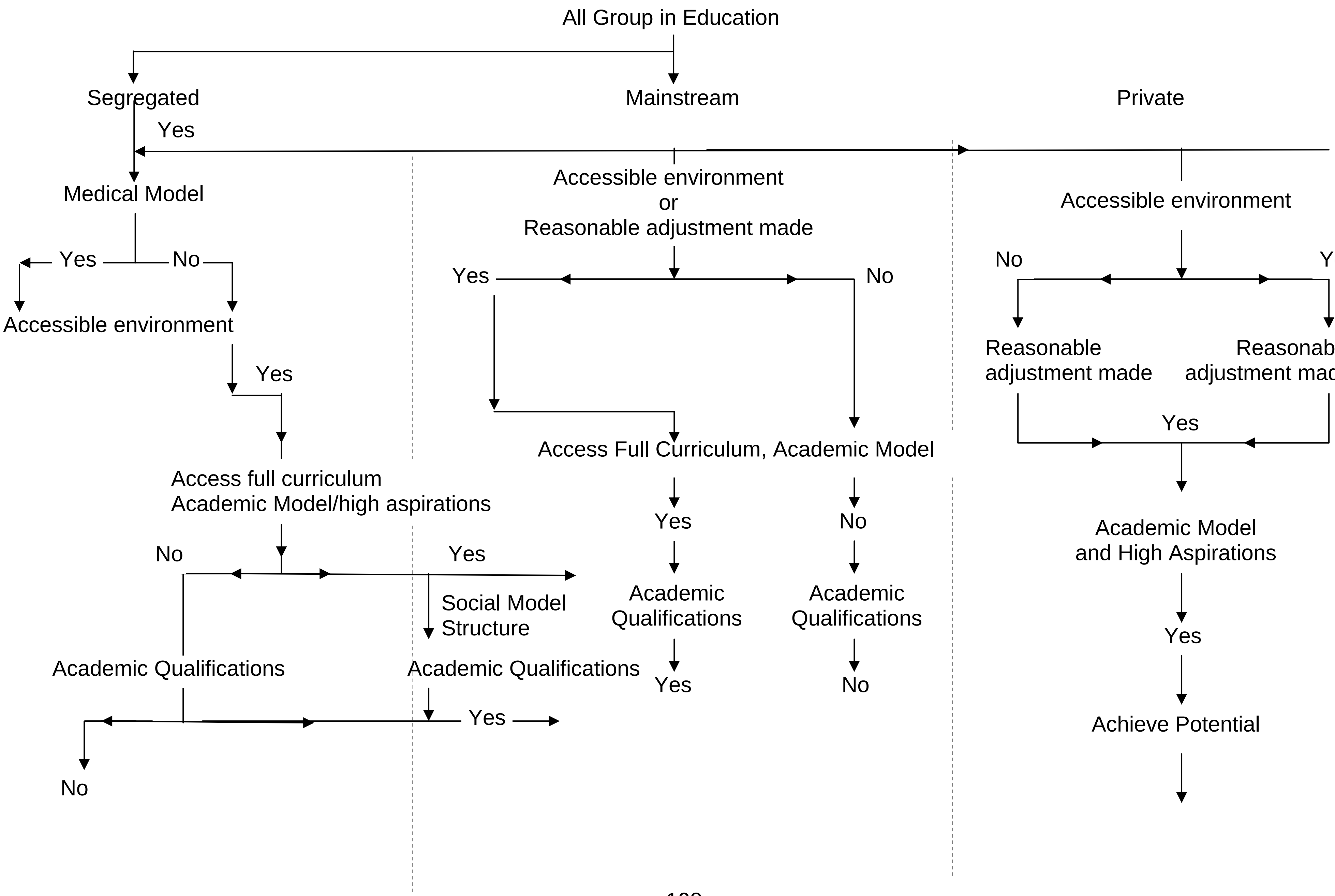
4.1 Social Capital
4.2 Application Process
4.3 Discrimination/Attitudes
4.4 Benefit system
4.5 Legislation/Institutions
4.6 Structural/Physical
4.7 Other

### 5. Enablers

5.1 Education/Knowledge
5.2 Culture of organisation
5.3 Disability awareness/employer support
5.4 ATW/Benefit System
5.5 Stepping Stones (Steps to Work)
5.6 Other (coping strategies/fitting in/minimisation)

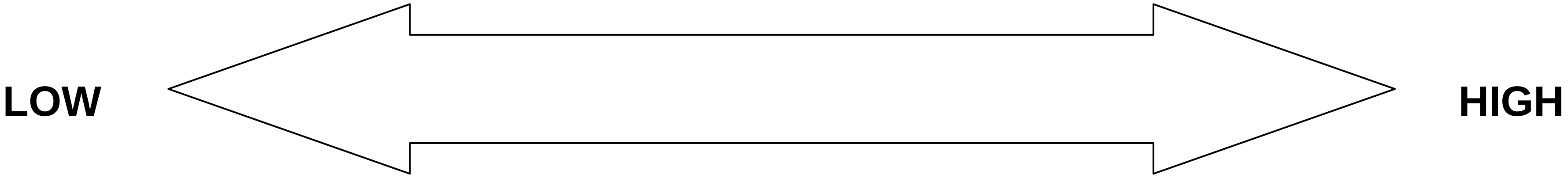
# Appendix 9

## Accessing Education



**Appendix 10**

## Motivation Level and Likelihood of Remunerative Work

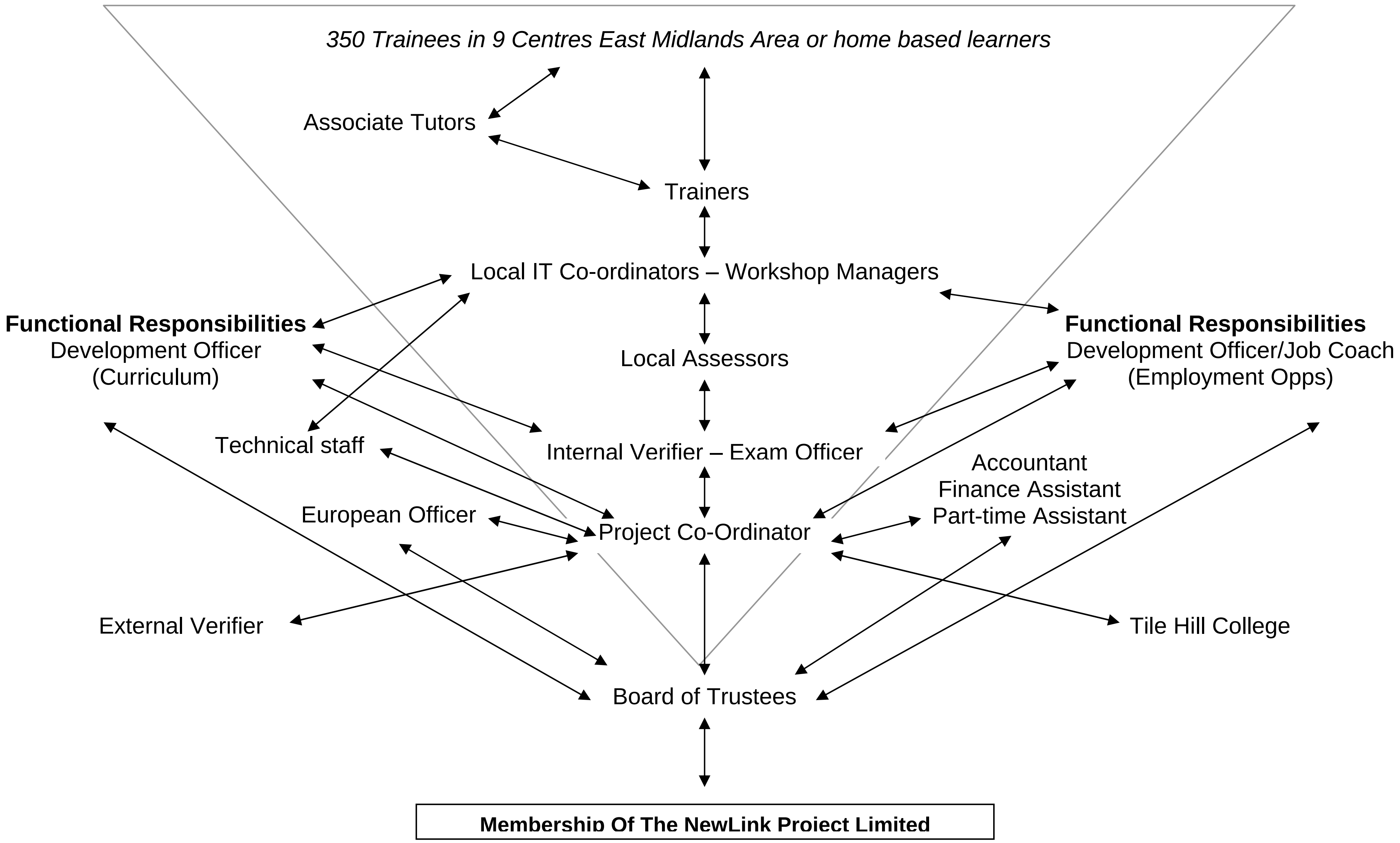


| Barriers | Enablers | Motivators |
|---|---|---|
| Benefit system | Social capital | Primary sector and skilled work |
| Low skilled low paid work | Benefit system [AtW, PW and DLA] | Job satisfaction |
| Physical access | Voluntary work | Accessible buildings and transport |
| Attitudinal | Knowledge of help and support available | Adjustments made |
| Impairment | Employers | Good employers |
| Employers | | |

**Appendix 11**

# Newlink Project – Responsibility Structure

## Line Responsibilities



## Appendix 12

## Suggestions for Policy

The main factor highlighted was the role that employers need to play.

‘Employers need to come on board with employing DP, or it just won’t work.’

Some respondents had experience of the quota system [now abolished] and felt that a return to this system would be beneficial, but only if the percentage level was set high enough; that it applied to all levels in the organisation, and was rigorously enforced. In particular this demand side measure was seen as a way that the public sector could discharge their Public Body Duty. The public sector was seen as an area delivering services to disabled people, but not with them.

Similar views on enforcement were raised with the DDA, also the need for the responsibilities [in the DDA] to be weighted more on the employer. Respondents viewed the DRC to have a role in enforcing the DDA, as it was considered that currently individuals had the odds stacked against them. All of the respondents felt that disability was the ‘poor relation’ in the current diversity agenda, and that the focus was diluted, and would be further diluted with the single equality body. Education for employers and co-workers was seen as key to achieve inclusion in work, with the DRC seen as having too low a profile.