

“I am really fearful of what is going to happen to me in the near future.”:

The impact on disabled people of cuts and changes in benefits and services.

Rosa Morris

2012

Abstract

This dissertation is concerned with two key issues: the impact of cuts in benefits and services on disabled people; and the role of disabled people's organisations (DPOs). Working with a local DPO, and using emancipatory research principles, the experiences of 95 disabled people were gathered using focus groups and interviews, and an online questionnaire distributed via social media.

These experiences confirmed that benefit changes are creating significant financial difficulties for some households, and that there is a cumulative impact of cuts in benefits and services. People spoke of the effect not just on their finances but also on their physical and mental health. Many of the respondents were fearful of what the future holds for them.

There was a general feeling that social attitudes towards disabled people had become more negative and some people had experienced verbal abuse. There was a low level of awareness about local DPOs but a general feeling that they were needed to provide advice, information and advocacy, and to campaign on disabled people's behalf.

Contents:

Chapter One: Introduction.....	4
1.1 Context.....	4
1.2 Origins of the research project.....	4
1.3 Structure of the dissertation.....	6
Chapter Two: Review of the literature.....	7
2.1: Welfare Reform.....	8
2.2: Social Care.....	17
2.3: Social Attitudes.....	20
2.4: Conclusion.....	22
Chapter Three: Methodology.....	24
3.1: Methodological approach: Emancipatory research.....	24
3.2: Data collection and participant recruitment methods.....	27
3.2.1: Questionnaire.....	28
a) Twitter.....	29
b) Facebook.....	31
c) Disability Research JISC-list.....	32
3.2.2: Focus Group.....	32
3.2.3: Internet Forum.....	37
3.2.4: Individual Interviews.....	38
3.3: Critique of the research methods used.....	39
3.3.1: Use of social media to recruit research participants.....	40
3.3.2: Focus groups: limitations and advantages.....	42

3.3.3: Involvement of disabled people in design of the research.....	45
3.3.4: Ethical Considerations.....	46
Chapter Four: Research findings.....	49
4.1 Experiences of changes to assessments for benefits.....	49
4.2 Consequences of changes in entitlements.....	51
4.3 Impact of cuts in social care and other local services.....	53
4.4 Advice, information and advocacy.....	57
4.5 Social attitudes.....	59
4.6 What should disabled people’s organisations be doing?.....	61
Chapter Five: Conclusion.....	65
5.1 Research findings.....	65
5.1.1 Impact on disabled people.....	65
5.1.2 Key messages for DPOs.....	66
5.2 Implications for further research to be carried out by HAFAD.....	67
Bibliography.....	69
<u>Appendices</u>	
1. Online questionnaire.....	77
2. Analysis of questionnaire respondents.....	81
3. Focus Group Topic Guide.....	83
4. HAFAD staff interviews Topic Guide.....	84

Chapter One: Introduction

1.1 Context

Disabled people are facing significant changes to the benefit system and the local services on which many depend. These changes are the results of the Coalition Government's policies on welfare reform and the general tightening of public expenditure in its attempts to reduce the deficit.

Despite the UK having once been seen as one of the pioneers in independent living, it would seem much of the progress made in relation to disabled people's rights is being reversed and "we find ourselves struggling to maintain what we have built up over the last 30 years" (Evans, 2011).

Disabled people's organisations, both national and local, played an important role in bringing about previous progress. Now they are struggling to respond to not only the cuts in benefits and services but also reductions in their funding. Voluntary sector organisations in general are facing an estimated £1.2bn cut in funding between 2010/11 and 2015/16 (NCVO UK Civil Society Almanac), while 20% of DPOs in London are currently facing closure (Inclusion London, 2012, p.4).

1.2 Origins of the research project

This dissertation aimed to work with a local disabled people's organisation, using emancipatory research principles, to test out

research methods that might be used in a larger research project which would measure the impact of these changes on disabled people and identify how DPOs should respond.

I have previously worked as a volunteer at Hammersmith and Fulham Action on Disability (HAFAD), a local organisation run by and for disabled people. HAFAD describes itself as an "independent organisation promoting equality for disabled people living" (<http://www.hafad.org.uk/index.asp?pageID=149>)

It combines providing services such as advocacy, assistance with form filling and managing direct payments with campaigning activity on local and national issues important to its members.

HAFAD's Director approached me a while ago about carrying out research on how the coalition government's changes to benefits and policies are impacting on their members. He wanted research which would inform the organisation's campaigning activity and its service development. He was keen to not only gather information from existing HAFAD members but also to explore disabled people's experiences more generally and in particular what they might want from a DPO like HAFAD.

Following our discussions we agreed that I would use the opportunity provided by my dissertation to carry out a small piece of research which would explore:

- a) the impact of the current cuts in services and benefits on disabled people
- b) what disabled people want from local DPOs in this context.

It is hoped that this research project could be preliminary to a larger piece of work, which HAFAD would seek funding for. As well as exploring the research questions, it would also be an opportunity to test out what might be the most productive research methodology to use in this larger piece of work.

1.3 Structure of the dissertation

The dissertation is divided into three parts: Chapter 1 provides a literature review which discusses both the relevant policy changes and current research about their impact on disabled people; Chapter 2 describes the research methods used, detailing how I went about recruiting participants and gathering data, as well as assessing the validity of the methods; Chapter 3 presents analysis of the data. Finally, the conclusion summarises the main findings and the implications for HAFAD's intention to carry out further research.

Chapter Two: A review of the literature on the impact on disabled people of cuts in benefits and services.

This chapter sets out the policy context in which disabled people are experiencing changes in benefits and services, and summarises what recent research tells us.

The current coalition government placed welfare reform and public spending cuts at the centre of their strategy to deal with the economic crisis. Disabled people are "disproportionately reliant on health, social care, housing and transport services, and also, as a result of low employment rates and the additional costs associated with living with an impairment, more likely to live in poverty and/or rely on benefits for a large proportion of their incomes", meaning they are "therefore likely to be directly and disproportionately affected" by such reforms and cuts (Wood and Grant, 2010, p.11).

Two main policy areas have a significant impact on disabled people's lives: welfare reform; and social care. This dissertation seeks to explore both areas and a summary of policy changes and what is currently known about their impact is set out below. My research findings concern, not only disabled people's experiences of benefits and services, but also evidence relating to changing social attitudes, and current research on this issue is therefore also discussed.

There is, as yet, limited quantitative data on the impact of changes in the two policy areas under discussion, primarily because of the short time span and also because some are still to be fully implemented. The current research literature relies predominantly

on case studies (e.g. Wood, 2012) and modelling (Morgan, 2012). It is also limited because, apart from the government's own research (e.g. Sissons, Barnes and Stevens, 2011) and statistics (e.g. Department for Work and Pensions, 2012), most of the current material on the impact of changes on disabled people is written from perspectives which are highly critical of government policies.

2.1 Welfare reform

The main welfare reform which has impacted on disabled people is the replacement of Incapacity Benefit with Employment and Support Allowance and the introduction of the Work Capability Assessment. The replacement of Disability Living Allowance with Personal Independence Payment is yet to be implemented and changes in housing benefit are still working their way through, though there is evidence of their impact from some of the case study research discussed below.

Much of the campaigning of disability rights groups over the past 30 years has been focused on getting governments and wider society to understand the structural problems that are often behind disabled people's reliance on benefits and services. Using the social model of disability it has been argued that it is disabling barriers within society which cause disabled people's poverty and social exclusion, rather than an individual's impairment or illness. The focus for policy should therefore be on removing these barriers and providing the additional support needed to create a level playing field. However, while the last and the current

government claimed to adopt the social model of disability, they promoted a rather different approach in the context of welfare reform. This is the bio-psycho-social model, developed by the insurance industry (Rutherford, 2007) and adopted by both Labour and Coalition governments in their goal of reducing the numbers on out-of-work sickness benefits. The bio-psycho-social model has had a direct impact on disabled people who are out of work in that it insists that “Personal choice plays an important part in the genesis or maintenance of illness” (Wade and Halligan, 2004, pg. 1400).

Building on this approach, a key argument behind the changes to out of work sickness/disability benefits has been centred around the idea that people have become dependant on welfare and need to be incentivised into work. Begun under the last Labour government this argument assumes that many people claiming these benefits are actually 'fit for work' but are 'festering' on welfare - according to Secretary of State for Work and Pensions, Ian Duncan Smith (Daily Telegraph, 2012).

The Work Capability Assessment (WCA) was introduced in 2008 to decide entitlement to Employment and Support Allowance (ESA). ESA replaced Incapacity Benefit as the out of work benefit for people considered unable to work due to sickness and impairment, with those already on IB being reassessed and moved onto ESA between 2008-2013. The WCA can have one of three outcomes. The individual may be assessed as: unable to work and placed in the ESA Support Group; able to work, with support, at some point in the future, and placed in the Work Related Activity

Group (WRAG); or found 'fit for work' and transferred onto Job Seekers Allowance (JSA). Of the two and a half million people who had previously been eligible for Incapacity Benefit, the government's intention is that, by 2015, one million would be found fit for work and therefore no longer eligible for long-term benefits.

The coalition government also brought in a limit of 12 months for claiming the WRAG component of contributory ESA, after which they have to claim means-tested ESA benefit. The government's impact assessment of this policy estimates 90 per cent of people in the WRAG group could be affected by this time limit and a third of these will not be eligible for means-tested ESA (Department for Work and Pensions, 2011, p.2).

Evidence of the impact of this new system on disabled people falls into three categories: research and statistics published by the Department for Work and Pensions; research which primarily uses case studies and modelling; policy analysis and anecdotal evidence by individuals and organisations campaigning against the changes.

Quarterly DWP statistics on decisions made on new (completed) ESA claims indicate that, when the benefit first replaced IB in 2008, 65% were found fit for work, 25% were placed in the WRAG and 11% in the Support Group. The most recent data, relating to the three months ending November 2011, show that 55% were found fit for work, 20% in the WRAG and 26% in the Support Group (Department for Work and Pensions, 2012a).

Forty-one percent of decisions relating to new claims for ESA have been appealed against. Forty-one per cent of appeals against decisions made when it was first introduced (December 2008-February 2009) were successful but by the quarter ending May 2011, this had dropped to a 31% success rate (Department for Work and Pensions, 2012a, p.9). However, there is evidence that the success rate is closer to 70 per cent if the appellant has representation (Franklin and Marsh, 2011, p. 14).

The DWP also published statistics relating to reassessments of those receiving IB. The data available up until the end of July 2012 show that 34% of those previously entitled to IB were placed in the Support Group, 29% in the WRAG and 37% were found fit for work. However, these statistics do not take account of appeals and this data is not as yet available. As DWP state, "it is likely that the statistics underestimate the proportion of claimants who will ultimately be awarded ESA" (Department for Work and Pensions, 2012b, p.2)

The DWP commissioned research on 'routes onto Employment and Support Allowance' (Sissons, Barnes and Stevens, 2011). Interviews were carried out with a sample of those claiming ESA between April and June 2009, with follow up interviews 18 months later. The most commonly reported health conditions amongst claimants were musculoskeletal conditions (37 per cent) and mental health conditions (32 per cent) but it is also striking that 66 per cent reported multiple health conditions and 53 per cent fluctuating conditions. The WCA has been particularly criticised for its failure to measure the impact of fluctuating conditions.

Fifty-one per cent of people had been in paid employment immediately prior to claiming ESA and of these 85 per cent had been in employment most of their adult lives. High proportions of those claimants (49 per cent) who had not been in paid work prior to claiming had no qualifications and/or reported having literacy problems. Almost one-third (29 per cent) had never worked or were long-term unemployed and 38 per cent had mental health problems.

At the time of the follow up survey, only 26 per cent of people receiving ESA who had been in paid employment prior to claiming had moved off the benefit and into work. Amongst those who had not been in work prior to receiving ESA, only 9 per cent had moved into employment. Earlier research commissioned by DWP found that, amongst those people claiming ESA but who were found fit for work, only just over one in ten (13 per cent) were in employment at the time of a follow up survey and, amongst those still out of work, health problems were the most common reason identified for not being in work (Sissons, Barnes and Stevens, 2011, p.5).

Disabled people's opportunities for moving off benefits (whether from the WRAG ESA or from JSA) and into employment are also likely to be affected by discriminatory attitudes amongst employers. Leonard Cheshire Foundation's survey carried out in 2009 found that 43 per cent of respondents reported being turned down for employment because of their disability or impairment (Gore and Parckar, 2009). The employment rate amongst disabled

people remains low in comparison with non-disabled people: in 2011, the employment rate of disabled people was 48.8 per cent, compared with 77.5 per cent of non-disabled people (Labour Force Survey, 2011).

There has been much controversy about the way the Work Capability Assessment is carried out and the DWP's own research indicates a high level of criticism amongst those, claiming ESA, who were found fit for work: 87% reported that the WCA report was not accurate and those with mental health conditions were particularly likely to feel that it was not accurate (Barnes, Sissons and Stevens, 2010, p.4) Professor Harrington was appointed to undertake an independent review into the WCA. His first review found that assessments were "impersonal and mechanistic" and that there was little transparency about how the process worked, with poor communication at key points. The result, he concluded, was too often "poor decision-making" (Harrington, 2010). He made recommendations for improving the process and his second review concluded that good progress was being made in implementing these (Harrington, 2011). The review described the further work that was being done on making the descriptors in the WCA more appropriate for those with mental health and fluctuating physical conditions but reported that changes still needed to be made. A third review is due later this year. In July 2012 it was announced Professor Harrington would be stepping down from his role of independent reviewer and he stated that the system was still "patchy" and "'traumatic' for many people" (BBC, 2012).

Citizens Advice Bureau has received increasing numbers of enquiries about the WCA and supported increasing numbers of people to mount appeals. Their analysis of their clients' experiences in the first stages of implementation led them to conclude that: seriously ill people were being inappropriately called for assessment; the WCA does not accurately measure fitness to work; and that the process is resulting in many inappropriate outcomes in terms of entitlements to benefits (Citizens Advice Bureau, 2010). In January 2012, Citizens Advice Bureau published an analysis of 37 WCA reports collected from their advice service clients. They concluded that the level of accuracy in the reports was "worryingly low" and this was true even where ESA had been awarded (Citizens Advice Bureau, 2012a). A survey by the Parkinson's Society found that, of those placed in the WRAG or found fit for work, ninety-three per cent thought decisions made about them by medical assessors were wrong (Community Care, 2009).

Analysis by Citizens Advice and Macmillan Cancer Care of helpline enquiries and advice work found that the WCA process was "not sensitive to the problems faced by people with cancer" and that people who were terminally ill and those receiving chemotherapy were asked to attend inappropriate assessments or work-focused interviews (Citizens Advice Bureau and Macmillan Support, n.d). Despite some changes to the WCA process, the organisation has continued to express concerns, based on experiences of their clients (Citizens Advice Bureau, 2012b).

Although there is, as yet, little large-scale research on the impact of the cuts in services and benefits, there has been much material published by organisations and individuals campaigning against welfare reform. These give an indication of some of the potential effects of the policies although it is difficult to know how representative the experiences are, or even how many people are similarly affected.

Some individuals have recounted the impact of losing contributions-based IB/ESA. One example is Mark Sparrow, a journalist unable to work because of significant health problems, who wrote

the £90 that I received each week since being unable to work has made an enormous difference towards paying essential bills like heating costs and council tax. Now this must fall entirely on my wife's shoulders. From now on I will no longer be able to contribute to the household budget and that makes me feel even more of a burden. It's bad enough that I can't do my proper share of the housework but the thought that I can no longer contribute financially has hit me hard.From tomorrow I'll lose the little bit of independence that I have at the moment. From tomorrow I'll have to ask my wife for some pocket money to pay for even my most basic needs such as a birthday present for a loved one or something as small as a cup of coffee. It's hard to describe how utterly impotent and dependent that makes me feel. From tomorrow I will be financially as well as physically disabled.
(Sparrow, 2012)

A key criticism of welfare reform has been the cumulative impact on disabled people of changes to the benefit system. There has not, as yet, been comprehensive research on the extent of this impact but some of the policy analysis and case study material indicates the potential for further research on this aspect of welfare reform. For example, both Citizens Advice Bureau and the Trades Union Congress argued that the 10 per cent reduction of housing benefit for people claiming JSA for more than a year is expected to fall hardest on those who face disadvantage in the labour market (Wood and Grant, 2010, p.55). As already identified, disabled people face higher unemployment rates than non-disabled people, which is at least partly accounted for by discriminatory attitudes amongst employers.

In a report commissioned by Scope, Demos calculated that – as a result of the 2010 emergency budget, disabled people and their families would lose a total of £9bn over the five years of this Parliament (Wood and Grant, 2010). Edwards (2012) estimates that “the poorest fifth of the 2.7 million households receiving disability benefits will lose 16% of their cash income” by 2015 (Edwards, 2012, p.4).

The Scope/Demos ‘Disability in Austerity’ project has been following five families to assess the impact of cuts in benefits and services. For example, the change from RPI to CPI used for uprating benefits is creating a steady reduction in benefits compared to what would otherwise been received (Wood and Grant, 2012, p. 39). However, perhaps the most worrying conclusion from this final report is that ‘the worst is yet to come’,

with, for example, reductions in council tax benefit, the change from Disability Living Allowance to Personal Independence Payment (with half a million people expected to be deemed ineligible), and further reductions in housing benefit entitlements. Some disabled people will lose out when Universal Credit is introduced, particularly those who would previously have qualified for Severe Disability Premium which is being abolished under the new system (Morgan, 2012, p.20). Reductions in Mortgage Interest Support have already been affecting some disabled people (as was evident from the Demos study) and further changes will affect more households (Morgan, 2012, p.22, p.83).

2.2 Social care

There are three main policy changes which are impacting on disabled people who need social care. Firstly, four out of five councils now only fund 'Critical' or 'Substantial' needs (Wood, 2012, p.18). This tightening up of eligibility is a result of cuts imposed on local government. The annual survey carried out by the Association of Directors of Adult Social Services indicates that £890m was cut from social care spending in England in 2012, and nearly £2 billion taken out of social care budgets in recent years (Local Government News, 2012).

Secondly, there has been an increase in the numbers of local authorities charging for social care services and an increase in the charges themselves. More than one in four people with learning disabilities (or their carers) who responded to a Learning Disability Coalition survey said that they had experienced an increase in

charges during 2010/2011 (Learning Disability Coalition, 2011, p. 4). For the year 2011/2012, Demos found that the majority of English local authorities (123 out of 152) had increased their charges, some by very significant amounts (Wood, 2012, p. 37). Some disabled people on direct payments have also reported that agency charges have increased but their direct payments have not kept pace, meaning they have to make up the difference out of their income (False Economy, 2012b).

Finally, the government closed the Independent Living Fund to new applicants in 2010 and intends to totally close it, although existing care packages are protected until 2015 (Department for Work and Pensions, 2012c). The Association of Directors of Adult Social Services told the Joint Committee on Human Rights that "with the majority of authorities having eligibility criteria of substantial or critical, there is little doubt that there will be many people who cannot now be assisted in the way that the Independent Living Fund was able to assist people"(Joint Committee on Human Rights, 2012, para 150). There are currently a total of almost 20,000 people receiving ILF grants (Department for Work and Pensions, 2012, p.10).

Evidence on the impact of these changes on disabled people's lives is patchy and incomplete. Some quantitative data is available in terms of levels of funding and numbers of people affected, or estimated to be affected. For instance, the Learning Disability Coalition carried out a survey of the 152 local authorities in England, achieving a response rate of 40%, which found that 20% were being forced to cut services and only 7% felt that learning

disability services were well funded (Learning Disability Coalition, 2011, p.8). However, most other evidence is restricted to case study data available from disability and carers' organisations, and – as mentioned above - from the Demos/Scope research project. One of their case studies was assessed by his social services department as needing more personal care but the amount of direct payment he received was reduced because of the local authority's increase in community care charges (Wood, 2012, p.65).

Amongst the anecdotal evidence is the example of one woman whose support has been reduced: "I have a 23 hour a week care package. It doesn't stretch across, so on the weekend, I tend to basically stay in bed. If I need more care hours in the weekend, I have to take it away from my other hours in the week, so there's no leeway" (False Economy, 2012a). Some of the case studies gathered by the Learning Disability Consortium illustrate the difficulties experienced by some families: "My sister, who has severe learning disabilities, has had ALL her care removed, with funding cuts being cited as the reason. It is not possible for the family to replace this care, as well as the support the family were already providing. We are also not trained to give the specialist services needed. My sister is now suffering from serious neglect certainly due to funding cuts" (Learning Disability Consortium, 2011, p.11).

More people may be forced into residential care as a result of the changes. For example, two local authorities have proposed a cap on how much will be spent support disabled people at home,

beyond which it is expected they will go into residential care: Newcastle City Council proposes to limit care packages to £500 p.w. (False Economy, 2012c) while Worcestershire County Council proposes to 'benchmark' homecare packages with the costs of residential care (Guardian, 2012a). One man, worried about the impact of such a cap on care packages, expressed his fear about what he would lose: "My 24-hour care allows me to live at home. It makes all the difference – it means you can still participate in your community...It's important to hold on to your normality and self-esteem. It's lovely to live almost a normal life – to go shopping, to have a social life, to go to church, to visit people, to be involved in activities" (Ibid).

2.3 Social attitudes

Another aspect of policy changes has been a shift in social attitudes. Some people argue that there has been an increasing tendency for the media (particularly some high circulation newspapers) to present disabled people as "lazy scrounging scum, perfectly able to work if they choose, draining resources from an already overburdened taxpayer" (Franklin and Marsh, 2011, p.43).

The recent British Social Attitudes survey found a reduction of public support for people in receipt of benefits but attitudes towards disability-related benefits seem more complex. For example, support for more spending on benefits for disabled people unable to work fell from 63% to 53% between 2008 and 2011 (Park et al, 2012, p.vi) but on the other hand the proportion of people believing that government should ensure "that people have

enough to live on if they become sick for a long time or disabled” remains high at 84% (p.5). The authors conclude that “People’s changing views may.... reflect a belief that people are being incorrectly classed as disabled or unable to work, rather than any ‘hardline’ view that disabled people do not deserve to be helped” (p.8).

Inclusion London commissioned the Glasgow Media Centre to carry out an analysis of news media coverage of disabled people between 2004 and 2011. The methodology involved content analysis of five newspapers, supplemented by detailed audience reception analysis using focus groups. The research found an increase in the coverage of disability and a shift in the way it was covered. The authors described a politicisation of the coverage of disabled people with a reduction in the number of stories about the lives of disabled individuals. There was an increase in stories focusing on benefit fraud and in articles presenting disability benefits as a ‘burden’ on the economy. The analysis found significant increases in pejorative language used to describe disabled people and concluded; “Disabled people are feeling threatened by the changes in the way disability is being reported and by the proposed changes to their benefits and their benefit entitlements. These two are combining and reinforcing each other” (Strathclyde Centre for Disability Research and Glasgow Media Unit, 2012, p.5).

In some cases, negative attitudes create disability hate crime – an offense only recognised by the criminal justice system in 2005 when the Criminal Justice Act 2003 became law. An Ipsos/Mori

poll in 2007 found that one third of disabled people did not feel safe in their neighbourhood, rising to nearly half of adults with a mental health condition (Scope, 2008, p.11). When Scope carried out research in 2008, one fifth of the disabled people in their survey said that they did not feel safe and secure at home or in their local community (Scope 2008). There has been no research as yet which would measure whether these feelings of insecurity have increased as a result of the increase in attitudes about disabled people being seen as ‘benefit scroungers’ and ‘a burden’, but the number of recorded disability hate crime incidents grew by almost 50% between 2009 and 2011 (Guardian, 2012b). However, it has been argued “that increased awareness, confidence and motivation to report and the efforts of the police and others make up for a large part of the increase in recorded [disability hate] crime” (Crowther, 2012)

2.4 Conclusion

Although there is a lack of comprehensive quantitative data on the impact of cuts in benefits and services on disabled people and their families, some of the research which uses a case study approach has the advantage of bringing to life the cumulative impact of the changes. The Demos/Scope research, in particular, in tracing the experiences of a group of households over the period of the changes in benefits presented a dramatic story of what households lost and how this impacted on their lives:

These losses ranged from £74.70 to a staggering £781.55 between April and October 2011, and some of the people we spoke to reported having to choose between fuel and food,

to cancel hospital appointments as they were unable to afford transport costs, and to let their houses fall into disrepair. It was clear that with each passing month the financial resilience of the households in our study was declining – savings were being wiped out, debts accumulating, and opportunities for one-off emergency grants were exhausted.

(Wood, 2012, p. 21)

The longer term and more fundamental impact on the case study households, the research concludes, are “an ever-diminishing civic and community life, the end of the safety net, deteriorating mental health, and the burden of care” (p.77). In summary, the cuts in benefits and services are “reducing their lives to the very basics of survival – often within the confines of their homes” (p.78).

The next chapter discusses in some detail the research methods used for this dissertation research project.

Chapter Three: Research Methodology

The origins of the research are explained in the Introduction. This chapter sets out the approach which guided my research, describes the methods used to recruit participants and gather data, and critically discusses these methods.

3.1 Methodological approach: Emancipatory research

In the early 1970s, research on disabled people living in an institution called Le Court epitomised the problems with much research about disabled people. Supposedly an objective and unbiased piece of research, the findings were influenced by the viewpoint that any problems were located within the body of disabled individuals. Any complaint they made about the running of the home or their wish for more control over their lives was therefore considered 'unrealistic' (Barnes & Mercer, 1997; Barnes, 2008).

Some participants in this research, who viewed the researchers as 'parasites' (Hunt, 1981) were instrumental in the development of the Social Model of Disability, which underpins emancipatory disability research (Barnes, 2008; Oliver, 1997). The social model is central to emancipatory disability research because its challenge to the traditional view of disabled people results in a challenge to the traditional underpinnings of social research, which views disabled people as passive subjects to be researched (Barnes & Mercer, 1997). It also highlights that traditional research has contributed to the continued oppression of disabled people (Morris,

1992; Oliver, 1992; Hunt, 1981) 'by depoliticising the political' (French, 1994).

Emancipatory research also challenges the belief that social research can be a 'objective' and 'impartial' as if 'knowledge' can exist in a vacuum uninfluenced by culture and society (Mercer, 2004). Instead it argues that not only is this impossible but that there are different ways of interpreting the same data which are all influenced by economic, political and cultural forces. As Barnes highlights, this is seen across all research disciplines, with examples as different as climate change or autism (Barnes, 2001). This view of research as being inherently political builds on the arguments of critical theorists who rejected the positivist view of research and knowledge production as being objective, and challenged orthodox views and knowledge about minority groups. The role of emancipatory research is not to simply gather knowledge but to challenge and change social structures which lead to the oppression of disabled people (Barnes and Mercer, 1997).

Proponents of emancipatory research argue that 'all research is political and research production can further the oppression of those who are the subjects of research' (Swain and French, 2004, p.13). This means that fundamental to emancipatory research is the power and dynamics of research production itself.

'Participatory' research also recognises this and attempts to break down hierarchical relationships between researcher and researched. It generally uses qualitative research methods in an attempt to gain more of an insight to disabled people's lives and

experiences and to involve them more in the research process. However, although this is undoubtedly an improvement on purely positive standpoints, it does not attempt to challenge understanding about disability (Oliver, 1997) or change who controls the research (Zarb, 1992).

This challenge to the social and material relations of research production is perhaps the toughest to adhere to and definitely one I struggled with during this project. I describe some of the difficulties in the discussion below, but throughout I tried to adhere to the following principles, identified from the literature on emancipatory research (e.g. Barnes, 2001, Stone and Priestley, 1996, Stevenson, 2010):

- Accountability: to the disability community in general and to those involved in the research in particular, with all methods and data analyses open and fully explained to all involved and the dissemination of the research available to all.
- Control: Disabled people should have more control over the research agenda and research processes.
- The Social Model: the focus of research must be on the disabling barriers faced by people with impairments and on “the demystification of the structures and processes which create disability” (Barnes, 1992, p.122),

- Politically open: emancipatory research rejects the belief that any research can be objective and aims to be open about the ontological and epistemological starting points.
- Methods: research methods should reflect the wishes and desired outcomes of disabled people. Qualitative research methods are often associated with emancipatory research whereas quantitative research has been associated with the individual/medical model of disability. However, both methods have proven to be useful in highlighting and challenging the oppression of disabled people (Barnes, 1992; 2001; Barnes and Sheldon, 2007; Mercer 2004). Whatever methods are chosen, it must be recognised that research is a 'social act' and that there are unequal power relationships involved (Barton 1999).
- Outcomes: research must aim to have practical outcomes, determined by disabled people, that work towards the deconstruction of disabling barriers. Although it is unlikely that any one piece of research will produce measureable outcomes, it can initiate or add to a growing body of work that contributes to change (Mercer, 2004, Oliver 1997).

3.2 Data collection and participant recruitment methods

The research project used three methods of gathering data: an online questionnaire; two focus groups; and individual interviews. I also tried, unsuccessfully, to set up an internet forum to gather data. The experience of testing out these methods and how participants were recruited is discussed below.

3.2.1 Questionnaire

A questionnaire was considered as it could provide a method of gathering information from a number of people in the relatively short time period available. HAFAD's Director was keen that the research included information from people who were not currently in contact with HAFAD. We discussed a number of different methods of how to reach such people, including placing requests for research participants in local papers or in community centres and services. However, the time-frame for my dissertation did not allow for the longer recruitment period that would be required. It is, however, a method that HAFAD might consider in the future.

Instead, it was decided the best way to extend the research beyond those already in contact with HAFAD – in the time available - was to open up the sampling group to the wider disabled population and use social media/the internet to recruit people to the research. This meant that only people with access to the internet would be able to complete the questionnaire and this issue is discussed in more detail later on.

I discussed the questionnaire with HAFAD and also looked in some detail at current research, in particular at the case study research by Demos, to help inform my research questions. I wanted the questionnaire to enable respondents to write about their experiences and felt that open ended questions would enable them to do this. I also felt that this approach would help reveal the detailed impact on people's lives, particularly the cumulative

impact. However, as my supervisor pointed out, people are more likely to respond to closed questions. I therefore decided on a mixture of closed and open-ended questions. Most respondents did take the opportunity to write fairly full answers to the open questions, a measure of the level of interest generated by the subject matter.

Survey Monkey (<http://www.surveymonkey.com/>) is a commonly used tool for online surveys. However, the 10 question limit for the free package was too limiting and I also noticed a number of online comments saying that Survey Monkey did not work properly on particular browsers. I tweeted about my frustrations with this and several people then suggested I used google docs as a host as this allowed for a limitless number of questions and also provided a good analysis service. The questionnaire is attached at Appendix 1.

Over the course of one month, the questionnaire was posted on three different forms of social media, which are described below while the advantages and limitations of using social media are further discussed later in this chapter. A total of 72 people responded to the questionnaire, 50% of them hearing about it through twitter, followed by 24% through the discussion list and 21% Facebook (see Table 1, in Appendix 2).

a)Twitter

I am an active twitter user with over 1700 followers. Several of these are disabled people and I hoped twitter would be a good source of recruiting respondents. However I was aware that this

would mean my survey sample would be biased and this is discussed below. I was also aware of twitter being fast moving and a single tweet only being able to reach a snapshot of people who may be reading tweets at that particular point in time. Also, if people do not have time to complete the survey at the point at which they read it, they would have difficulty accessing the link later, unless they 'favourite' it. This all meant that the timing of my tweets was important and also that the use of hashtags could be useful.

Hashtags are used so that if people click on a hashtag related to a topic they see any tweets tagged with that hashtag. This also means people see the tweets of people they might not be currently following. This is one way of targeting specific 'communities of interest' and is similar to the 'snowballing' method which uses social networks to recruit participants (see for example Browne, 2005) but in this case the network is a virtual one.

I first posted the link to the survey on a weekday evening when two television documentaries were broadcast about ATOS and the Work Capability Assessment. This meant that a number of people were on twitter discussing the documentaries and more likely to see my link than at other random times. I had a good response rate and also a number of retweets. Retweets mean that all the people who follow the person who retweets my tweet will also see the link even if they do not follow me. Retweeting, like hashtags, is therefore also a form of 'snowballing'. However, I found the initial response rate dropped off very quickly. This is undoubtedly a result of the previously mentioned fast turnover of twitter.

I then tried using hashtags to increase the response rate. I used #wrb, which has been used during the last year or so for tweets about the Welfare Reform Bill, #DLA, used for tweets about Disability Living Allowance, and #WCA, used for tweets about the Work Capability Assessment. This produced an instant spike in response rates, but rapidly fell away soon after the tweet had been posted.

I tried tweeting the link at different times of the day and week to see if there was a difference in response rates. Although I thought early to mid weekday evenings would probably be the time of day most people might be accessing twitter, I found that tweeting the link on a Sunday evening resulted in the highest responses. This is of course a completely untested method and it may have simply been more people who both follow me and might be impacted by changes and cuts to disability related benefits and welfare were online at that particular point on that particular day.

b) Facebook

Facebook was also used to post the online questionnaire. In order to be seen by people who were affected by the policy changes I posted it on relevant group pages, such as Disabled People Against the Cuts and the NUS Disabled Students Campaign, although this would mean my sample would be biased towards those who had negative experiences. However, this also resulted in several people posting it on other groups, e.g. a regional group and an impairment specific site. This is another example of the

snowballing sampling gathering method that social media can produce.

c) Disability Research JISC-list

I also posted to the Disability Research list, a mailing list "intended for all those interested in research as it affects disabled people". I had a fairly good response to this and several people contacted me saying they had forwarded the link onto other people.

3.2.2 Focus group

Following discussion with HAFAD staff, I decided to recruit a focus group from amongst HAFAD's current membership. This meant I would be using a convenience, non-probability sampling strategy, as my sample population would be chosen from those that were 'close at hand' (Punch, 2005). A number of recruitment methods were explored.

The first was a mail-out to all the organisation's members - both those on the email database and by post. This became too complicated to do by post within the time frame so it was decided to use the email database. This meant that only those members who both had email access and had given HAFAD their addresses were contacted. At the same time, HAFAD offered to ask members of an existing group, the Expert Patients Group, if they were willing to participate in a focus group discussion.

Neither of these methods proved fruitful. Only one person responded to the email contact, and a failure of communication

(within HAFAD), partly related to staff sickness absence, meant that the letter I wrote to be given to members of the Expert Patients group was never distributed. If I had been 'on the spot', rather than only intermittently in contact with HAFAD, this would undoubtedly have made a difference. I therefore tried to have closer and more frequent contact with the organisation, and also to make contact with more members of staff.

This approach paid off. I established contact with a couple of members of staff who were very enthusiastic about the project, and HAFAD arranged for an intern to assist with recruiting people to the focus group. We telephoned people on HAFAD's list of members who previously indicated interest in events or discussion groups. This enabled immediate responses and also meant they could ask any questions they might have about participating. This more direct form of contact proved fruitful and we soon had seven people who were interested. However staff at HAFAD warned me there was often a high number of 'no shows' to things they organised, often due to the unpredictability of individuals' impairments and transport needs. We offered to pay people's travel costs but I was advised that in order to recruit a group of about 8-10 people I should invite around three times this number.

At this point I was fortunate to get the support of HAFAD's Welfare Benefits Manager who has a lot of direct contact with members through his form-filling support service. Once he started asking people if they were interested we soon had 24 people saying they would take part. This high response rate was probably because people knew and trusted him and also users of his service were

likely to have had recent assessments or reassessments of benefits and services and to have views that they wanted to discuss.

On the day, 22 people came, which was a lot more than I had expected given the previous warnings of high numbers of 'no-shows'. Talking to a few of the participants there seemed to be some confusion as to why they were there and this made me wonder what they had been told about the research by HAFAD staff who spoke to them. This experience made me realise the need to ensure I have more of an input in recruiting people for future focus groups and that all participants receive written information regarding the research before attending.

The high number of participants made my first experience of running a focus group quite a tough one. However the fact that so many people came indicated the relevance of the research subject. HAFAD staff said they had never seen such a high turnout for such an event, which seems to back up the suggestion that this is an issue of particular importance.

In preparation for the focus group, I arranged for another volunteer to chair the group so that I could concentrate on facilitating the discussion. I had 3 main headings of the themes I wanted to cover, with prompt questions to be used if necessary (see Appendix 3). I used both a tape recorder and my laptop to record the discussion. I, the volunteer and the intern welcomed people as they arrived, checked whether they had any access needs and

offered refreshments. The discussion lasted for 2 hours and allowed for comfort and refreshment breaks.

I had decided that the best way to structure the group was to get people to discuss some questions in pairs or groups and then come back to the larger group and talk about them. I had hoped this method might help those who were uncomfortable talking to a larger group of people and planned that the volunteer and I would try to make sure everyone participated. I had also decided that, as I wanted to test my methods and get feedback as to what could be improved, I would ask focus group participants to give me feedback on the questions used for the online survey. I therefore gave them copies of the survey at the beginning of the focus group, and asked them to discuss them in pairs or small groups. However, many people started to fill in the survey itself rather than considering how it could be improved.

One of my main fears of using a focus group to gather data was that some people might dominate the discussion, preventing others from contributing and risking their opinion being seen as the group's opinion when it comes to data analysis (Smithson, 2000). This fear was also expressed to me by several participants due to the large number of people who turned up to the focus group. It was suggested that perhaps several smaller groups were arranged for a future date instead. However when this idea was put to the group as a whole it soon became apparent that several people would find it very difficult to come back at a later date. This also highlighted how difficult it had been for people to attend in the first place, which shows some of the problems with using a focus group

in disability research. Accessing focus groups can be a lot more complicated for disabled people due to both disabling barriers such as access to transport and PA availability, and impairment issues such as fluctuating and chronic conditions. For example one woman had had to stop eating at 1pm the previous day to prevent a potential flare-up of Crohn's Disease on the day of the focus group. Several others had had to arrange transport and PA support a week in advance to ensure they could attend.

Following discussion, it was decided that we would continue with the focus group on that day but also offer both a smaller focus group the following week and individual interviews, either at HAFAD or in a place of people's choosing, for anyone who wished to talk further.

I suggested that those who definitely could not attend a future smaller group or interview should begin the discussion. Once the discussion began I found that it moved quite quickly and did not need much prompting or involvement from me, although I used the Topic Guide to ensure all themes were all covered. I was aware of the issue of "dominant voices" and tried to ensure that everyone was given an opportunity to speak. I found it difficult that group members assumed that I had no personal experience of disability. While I felt it was not my place to share my personal experiences, I was also aware that there is some evidence to suggest people are more likely to talk openly in a focus group if they perceive the facilitator to be of a similar background (Smithson, 2000).

As a result of the interest expressed at this focus group, four people attended a second meeting the following week and I interviewed one other person. I had decided to start this second focus group by discussing the main themes that had arisen from the larger group. However one person started to dominate the discussion. This was very difficult to deal with as she talked about something that was traumatic and distressing for her. I did not want to in any way dismiss these concerns or prevent her from gaining benefit from telling others about these experiences. I used several tactics to try and bring other participants in. However each time I tried, the woman with the 'dominant voice' soon took over the discussion again. Although this highlights one of the central potential problems with focus groups, I also felt that this woman did get a lot from sharing her experiences. Overall it provided me with some good experience and insight to how I might structure future focus groups in the larger project for HAFAD.

3.2.3 Internet Forum

Previous studies have suggested that participants are more likely to talk frankly using an internet forum than more traditional face-to-face methods (see Thelwall, 2008; Harvey et al, 2007). As someone who has experienced mental health issues I found the use of online support forums to be particularly helpful and wondered whether there was a way to incorporate this into my research methods. I also thought that it could work as a tool to enable disabled people involved in the research to have more control. A forum could provide a space where people can dictate the topics, participate in discussions at any time of the day that

suited them, and perhaps result in more useful data in terms of both how people are experiencing the cuts, what the most important issues are and how a DPO can best respond.

There would be a number of issues to consider if such a method was used. These include how public the forum would be. It is possible to make a private forum, however it is then much harder to truly know who the members are. There is a risk of people lying about their identity which could result in problems with the research outcomes or, much more seriously, present a risk to other members. There is also an issue of how to deal with potential 'trolling' of the forum or its members. There is also the potential of having to deal with someone posting about harming themselves and what the forum moderators, and researchers, can or should do in such a situation.

However, I have experience of being a moderator on an internet forum and decided that it would be worth trying out using such a method to gather research material. In the event, we were not able to recruit enough people to run such a forum owing to the time-scale for completing my dissertation. I still think an online forum has the potential to be a very useful tool for emancipatory research. However, I would draw on the experience of other researchers who have used this method, for example Sharkey et al (2011) who recommend using an experienced group of forum moderators.

3.2.4 Individual interviews

I offered one-to-one interviews as an alternative to participating in the focus group, should anyone prefer this method. I also aimed to interview HAFAD staff to explore their knowledge of disabled people's experiences, gained from their contact with service users.

An interview schedule was designed using the same themes and prompts as for the focus group. In the event, however, only one person opted for an interview rather than participating in the focus group and there was only time to carry out one interview with a HAFAD staff member. Nevertheless, it was important to offer the option of an alternative to the focus group as not all disabled people will be comfortable discussing personal experiences in a group setting. Moving forward into the larger project of research for HAFAD, more individual interviews would be useful for collecting in-depth experiences. The interview with the staff member provided valuable background information about the impact of cuts and changes in a variety of situations and also an idea of changes across time and in relationships with local authority and funding bodies. When it comes to doing the larger piece of research, individual interviews with all of HAFAD staff would be a way of exploring these issues across all of the services HAFAD provide.

3.3 Critique of the research methods used

The research carried out for this dissertation has enabled a testing out of a range of methods which might be used for the intended larger research project which HAFAD wishes to do. While it has produced some interesting and useful findings, which are discussed in the next chapter, there have also been some

methodological shortcomings which have lessons for the future work. In particular, the way questionnaire respondents were recruited created limitations on the representativeness of the findings; and the experience of the focus group discussions had implications for the qualitative data. These two aspects are discussed below, followed by a critique of the involvement of disabled people in the research and a discussion of the ethical issues raised.

3.3.1 Use of social media to recruit research participants

Using social media to recruit research participants had both advantages and disadvantages. The primary limitation associated with this method is the fact that 34% of disabled people have never used the internet. Only 10% of non-disabled people have never used the internet which means that disabled people are three times more likely to have never used the internet (Office for National Statistics, 2012).

There are a number of reasons for this. Disabled people are disproportionately more likely to be living in poverty (Palmer, 2007) and so less likely to be able to afford computer and internet access. They may also experience environmental and attitudinal barriers to using publically available computers and the internet itself is not always accessible to, for example, people with visual impairments.

The age and gender of the respondents illustrates the limitations of social media for recruiting research participants. Three out of four

respondents were women and only one was over the age of 65. However, although internet use is highest amongst younger people generally, my respondents were not skewed towards the youngest age groups, with 58% being aged between 40 and 64 (see Table 2 in Appendix 2). It is difficult to compare the impairment/disability breakdown with the available national statistics on disabled people generally: the largest category of respondents was those reporting multiple impairments (36%) which is not a category recorded in national data. Those reporting chronic illness were under-represented amongst the respondents while those reporting physical impairment or mental health problems were over-represented in comparison with national data (see Office for National Statistics, 2010, pp.34 and 37). There were no respondents with learning difficulties.

However, there were a number of advantages associated with using social media to recruit participants. There were no costs associated with disseminating the questionnaire, other than the time taken to post it on twitter, facebook and discussion lists. This is an important consideration for local DPOs who generally do not have access to research funding.

While there is increasing literature on the use of online surveys, there has not yet been much assessment of the use of twitter as a research recruitment tool in the particular way I used it, for example my use of related hashtags. However Sibona and Walczak (2012) have suggested that research which used a purposeful sampling technique to recruit participants through twitter - by tweeting directly at users they felt were most likely to

respond to a survey - was a successful recruitment tool. The recent initiative funded by the National Centre for Research Methods, looking at the implications of social media for research methods, will be a useful future resource for researchers such as myself (see <http://www.natcen.ac.uk/nsmnss/index.htm>).

My experience indicates that there are ways of using social media which enables a reaching out to relevant 'communities of interest' and this can increase the response rate. At the same time, of course, this can bias the results as those responding are those most likely to be (negatively) affected by – in the case of this research project – the cuts and changes in benefits and services. However, as will become clear in Chapter 3, the questionnaire did elicit some detailed responses which give an insight into the experiences of some disabled people even though other sources would be required in order to estimate the extent of these experiences amongst the disabled population.

3.3.2 Focus groups: limitations and advantages

As discussed above, there were some significant difficulties and limitations with the two focus groups and certain issues will need to be addressed if this method is to be used for the planned larger piece of research. The recruitment methods resulted in too large a group and some confusion amongst participants as to why the discussion was being held (which raises an ethical issue as discussed below). There was also a 'dominant voice' in the second, smaller, group which limited the contribution made by other participants.

Nevertheless, these limitations were a result of my own inexperience rather than being inherent to focus groups as a method. Moreover, in spite of the difficulties, the recording of the discussions produced some very rich data, as is evident from the next chapter. Focus groups can undoubtedly be a very useful method of gathering people's experiences and also enable research participants to have more control over the discussion and evidence (Wilkinson 1998). This is particularly important for emancipatory research as it means the research can be driven by "the respondents' hierarchy of importance, their language and concepts, their 'frameworks for understanding the world'" (Kitzinger 1994, p. 106). Participating in the focus group in and of itself also has the potential to be an empowering experience as it should be somewhere where participants can air and discuss their experiences (Wilkinson, 1998).

The richness of data produced using focus groups has also been described as "more valuable many times over than any representative sample" because "by discussing collectively their sphere of life and probing into it as they meet one another's disagreement, will do more to lift the veils covering the sphere of life than any other device I know of" (Bulmer, quoted in Flick, 2006, pg 191). This can lead to a greater understanding of particular experiences (Kitzinger 1994; Morgan, 1997) and prevents the depth and content of the discussion being dependant on the knowledge or perspective of the researcher. This method should therefore assist in collecting data on the cumulative impact of a wide range of changes in benefits and services, without prompting

from the researcher. It should also mean that the data collection is directed more by the participants than the researcher. Using a focus group can also avoid approaching disability as an individual experience as it is the group, rather than the individual, which is said to be the main unit of analysis (Kreuger, 1994; Morgan 1998; ref in Smithson, 2000). This makes it more likely that the research will be underpinned by the social model rather than medical model of disability.

One issue with focus groups is whether people feel comfortable discussing potentially personal and upsetting topics, particularly topics which they might feel they will be judge negatively by others about. As a focus group is seen as a public rather than private sphere it is more likely that people are directed by normative narratives and less likely to bring up issues outside of this narrative than in perhaps an individual interview or anonymous questionnaire - although these are also affected by normative influences (Smithson, 2000, pg 113). However one of the things I was surprised about with the focus groups was how open people were and how many spoke frankly about mental health problems, a subject which can often be difficult for people to speak about publically. This would reflect Wilkinson's findings that focus groups can facilitate "the expression of difficult or taboo experiences in a group context" and that "one person's revelation encourages others to disclose similar experiences" (Wilkinson, 1998, pg 119). Although of course there is no way of knowing what subjects relating to the research questions that people may have found too personal or taboo to discuss, it was interesting to note how once one person spoke about having mental health problems others

began to share their experiences, and several people said afterwards how helpful it had been talking to other people who they felt understood their experiences.

3.3.3 Involvement of disabled people in design of the research

One of the most important principles of emancipatory research is the involvement of the 'researched' in its design. Very quickly it became clear to me that this was going to be difficult to fulfill. HAFAD is a disabled people's organisation and they had decided that this would be a useful research subject for them. However due to both practical issues surrounding some individuals' availability and a limited amount of time, the role of HAFAD staff in designing the research was not as in-depth as it could have been. I did meet with HAFAD staff at each point of the research design and get feedback from them. However this is not the same as if they had been truly directing it. I was also aware that if the research was to be emancipatory perhaps it is those taking part in the research that need to be in control and involved in its design. Despite HAFAD being a DPO it could still be possible for them to develop an 'expert' role in which they dictate what is researched and fail to represent the voices of those that are the 'researched' themselves. One aim of this research project was therefore to find out how research participants would want to approach the research and what they thought would be the most useful and appropriate methods.

One way of doing this was the previously mentioned method of asking the focus group to review my questionnaire and give

feedback. However, this confused people and in hindsight I should have approached it differently. Everyone attending the focus group had so much they wanted to say about their experiences that it would have been better to have had a separate group to discuss the research questions and methods. Despite this the fact so many people attended the focus group and had so much they wanted to say could be seen as proof the research questions were ones people wanted to be researched. I did get some feedback from people regarding the research methods but this mainly related to issues such as the size of the initial focus group. There were also suggestions of having some focus groups which were more geared towards discussing one particular aspect or area of the cuts and policy changes. However others felt this might restrict the potential of the research to discover and display what the cumulative impact of the cuts and changes are on disabled people. Others felt individual interviews would enable me to get more detailed accounts of people's experiences. I only did two individual interviews but, when moving forward with the larger piece of research, individual interviews should probably play a larger role.

3.3.4 Ethical Considerations

The use of qualitative research methods means several ethical issues need to be considered (Silverman, 2006). Punch identifies that "Most concern revolves around issues of harm, consent, deception, privacy and confidentiality of data" (Punch, 1994, p.89)

There are a number of ways research could be 'harmful' for participants - from emotional distress caused by taking part, to the

research outcomes being used in a way that ends up causing harm to participants (Social Research Association, 2003). While it is "impossible to anticipate all potential harm" from participating in research, a researcher does have an obligation to protect participants from potential harm as much as possible (Ibid, pg 35). It is important to ensure all participants are fully informed about the research before participating, in order to avoid unnecessary confusion, offence, or intrusion. This is something that it appeared did not happen with some people attending the larger focus group, due to a lack of direct communication between myself and those attending. However I did ensure that, before the discussion began, everyone was fully briefed as to what the research was for and how the focus group fitted in. I also gave an opportunity to anyone to ask any questions before the group began and it was one of these questions which alerted me to the lack of clarity given to some participants prior to the focus group. Although this immediately concerned me and raised issues of potential 'deception' of participants, it did allow people to express and discuss a number of alternative research methods and approaches. I ensured that before then starting the focus group everyone was still willing to participate and that they were welcome to leave at any point. Confidentiality was also stressed, as was privacy over data. It was agreed that the discussion would be recorded and stored on a private laptop and that any direct quotes used in the research would be kept anonymous. I also offered all participants the option of reviewing the transcript of the discussion before anything was written up into the report. At the end of the focus group discussion, a member of HAFAD's staff came in and

offered support should any individual wish it and also reassured them about HAFAD's future.

Another ethical consideration is about enabling participation of those that may be otherwise excluded (Social Research Association, 2003 pg 37). The Social Research Association lists the potential barriers to participation as "communication, disability, comprehension or expense" (Ibid). By ensuring the focus group and interviews took place in an accessible venue and offering to cover transport costs I hoped to make participation more inclusive. Participants were also asked in advance what additional access needs they might have, for example communication assistance. Perhaps the fact that no one stated they did have access needs demonstrates that there was a certain amount of prior exclusion from participation. This could also be related to the methods used to find participants and future research needs to consider this and how 'harder to reach' groups can be included (see Emmel et al, 2007).

As previously mentioned, this research is intended to try out methods for a larger research project which HAFAD hopes to get funding for. There were a number of lessons learnt and these are summarised in the conclusion. The next chapter presents an analysis of the data gathered from the online questionnaire, the focus group discussions and the interviews.

Chapter Four: Research findings

This chapter presents analysis of the material gathered from the two focus group discussions, the two interviews and the 72 questionnaires. First, I discuss people's experiences of the reforms to the benefits system before looking at experiences of adult social care. A common message from participants was their need for information, advice and advocacy and this is therefore dealt with as a separate section before moving on to discuss experiences of public attitudes towards disabled people and then, finally, what respondents wanted from disabled people's organisations.

4.1 Experiences of changes to assessments for benefits

The change from Incapacity Benefit to Employment Support Allowance (ESA), saw a change in how people are assessed for benefits when they are too ill to work. The Work Capability Assessment (WCA) replaced the Personal Capability Assessment when ESA was introduced in 2008. A small number of people from both the focus groups and who completed the questionnaire had experienced a WCA.

The general feeling amongst focus group participants who had had a WCA was that the experience was "degrading" and "humiliating" and that those doing the assessments were "judging" them and had "a total lack of understanding and knowledge" about their impairments or ill health and their capacity for employment. Two women spoke about how the assessment and its outcomes had a negative impact on their physical and mental health. One spoke of

"being put on anti depressants and blood pressure tablets after the experience of WCA" and another said "within a week of having WCA I had a breakdown, a psychotic episode". Both of these women were found 'fit to work' following assessment.

This detrimental impact of the WCA was also experienced by some people completing the questionnaire. One woman wrote that the process "is extremely stressful and has caused me great anxiety because it is unjust, inhumane and highly inaccurate in determining fitness to work". Another said that it was "making me even more severely ill and more disabled". Both these women were placed in the Work Related Activity Group ESA group following assessment.

A number of respondents were awaiting a WCA and expressed considerable fear about what they might experience. One wrote:

"The WCA and PIP plans have got me really worried. My main condition is Lupus but I also have arthritis, osteoporosis, asthma, COPD, auto-immune hepatitis and other minor conditions. I don't LOOK ill/disabled though and I am now really scared about losing benefits. I know I couldn't hold down a job - even if I could get one and the benefits I get enable me to live as normal a life as possible. I am also scared now to even try to do anything to make improvements in my health for fear that these efforts will be used against me. E.g. I can sometimes walk a short distance but if I do will they tell me I'm okay? Am I not better just to stay in my wheelchair?... I am really fearful of what is going to happen to me in the near future."

Questionnaire respondents and focus group participants expressed fear about the forthcoming change from DLA to PIP, and in particular a concern that an assessment similar to the WCA would be used to determine eligibility. As one focus group participant said, "You're made to feel like you can't have a 'normal life' or do anything as it'll be used against you to say you aren't really disabled". Some people were worried that the aids and adaptations they had to enable them to go about their daily life would mean that they did not qualify for PIP.

4.2 Consequences of changes in entitlements

The consequences of changes in entitlements amongst both those who completed the survey and who attended the focus groups appear to have been largely negative. However, as previously mentioned, this is perhaps unsurprising as those completing the online questionnaire or attending the focus group are more likely to be motivated to do so due to negative experiences. Only one woman who responded to the questionnaire reported that her benefits have been increased and that this had improved her life "immensely" while others wrote of reduced or withdrawn entitlements to support.

Most people talked about increasing poverty. The one year time limit on contributions-based ESA (which was retrospectively introduced from April 2012) meant that a number of participants found they were no longer entitled to out of work sickness benefits. One woman, for example, had used up her one year contributions-

based ESA and, “because my husband has a small pension, I can’t claim anything...So now I earn nothing, after working for 38 years, bringing up a family too, who all work. I do not exist!”. This sense of injustice was common amongst those facing this situation, as was anger at losing financial independence: “The decision to limit ESA in the WRAG groupto 1 year non-means tested means I lose all my benefit when I get moved to ESA. Whilst I have a partner who can support me, I lose my dignity and financial independence.”

Any gap in benefits payments due to changes or assessment outcomes which are then overturned at appeal can have a huge impact. One woman wrote that having her benefits stopped for a month before being reinstated meant that “all our direct debits got cancelled when my benefit didn't go in. All my creditors are now after me because I cannot cope any more to sort it out our home is at risk because of the drop in income. I feel suicidal want to self harm lost the will to live.” A number of respondents reported experiences which similarly indicated the precarious nature of households’ finances when dependent on benefits. For example one person wrote of how the wrongful withdrawal of DLA for a year meant going from “being very ill but independent, to chronically ill and totally dependent”.

Some respondents spoke of their difficulties in complying with the conditions attached to Job Seekers Allowance and of a consequent increase in dependency on others: “I was not able to go to Jobseekers appointments because my health wasn't good

enough, so I had to move back in with my parents so that I could afford to live and receive care”.

A number of respondents were worried about whether they would be entitled to PIP when it replaced DLA and the significant financial consequences this would have for them: As one woman wrote: “The changes with DLA worry me, I would have virtually no income without this and illness led to being forced to retire early which I hated as I loved my work” while another said “Proposals re DLA and PIP... all make life prospects insecure and frightening.”

Cuts to non-disability-related benefits have also had a huge impact on some respondents. For example one man reported that a “devastating” reduction in housing benefit by £330 per month has meant “Reduced amount to spend on food and combined with increased energy costs are pushing us into a spiral of debt. Had to use foodbanks”. Another had experienced a 10% cut in housing benefit and this had a significant impact: “I now worry about how much food I can afford. It's difficult because I urgently need to try and rebuild wasted muscle (as I'm at a rare point in my illness where that's possible) so I need protein but it's hard to get enough. I'm usually hungry for most of the day and I just have one big meal in the evening so I don't have to sleep in that state”.

4.3 Impact of cuts in social care and other local services

The online questionnaire, the focus groups and the interviews also covered experiences of changes in social care and other local services. There was one reported positive experience in terms of

changes to social care: "I've been given more hours of care (in the form of direct payments so that I can hire a PA) I've also been given funding to attend a day centre once a week....I've been more independent and spend less time in hospital now that I have the care I need. It costs my local authority less to prevent my problems than it costs the NHS to care for the aftermath of me being left to care for myself."

However, while this was one experience of increased support leading to increased independence, other respondents' experiences were of reduced support leading to increased dependency. For example one woman spoke of "going without desperately needed equipment and treatment" as "neither the NHS or local authority will fund them" and "as a consequence, my health is deteriorating rapidly and significantly". Another woman experienced eight months during which all her social care had been withdrawn due to what turned out to be a wrongful assessment. This lack of support resulted in frequent falls and a deterioration of her physical and mental health.

Some people reported how reductions in social care services affected family relationships. For example one man who took part in the focus group spoke about how his hours of care were cut following a reassessment, resulting in increasing pressure on his family. He now fears for the future of his marriage as "before getting that support my wife was a week away from walking out due to not being able to cope" and for his wife's mental health.

Some people were affected by reductions in the availability of both health and social care. One man with mental health support needs reported that services he had previously received have “all virtually disappeared. No OT available, no CBT available, I don't even have a qualified mental health worker now”. One woman with cancer found that the “day hospice shut the week I was diagnosed, receive no council assistance re disability....I could do with some help around the house but can't get any”.

Even where people manage to get increased support, they may sometimes still be impacted by changes in services:

“Our needs have increased as our health has got worse so we have had some additional services. But when mental health services redesigned their service, we suddenly lost all our familiar support staff. I am angry at services for changing all their staff without telling us first. Their workers are also obviously worried about their jobs. This affects us. I am more stressed and feel like I can't rely on services for support. I worry that there will be more cuts.”

Disabled people are not only being affected by reductions and changes in services but also by the charges made for social care support. For example one woman reported that increased charges meant “I have less money for other bills. I'm in arrears with my rent. Going out is a thing of the past”. Another spoke of how she can no longer afford additional costs associated with her impairment: “I'm broke....my SDA is now taken for my care, whereas it only used to be the care component of the DLA. This

means my very expensive and vital extras are now no longer covered, I have to reuse drinking straws for example because the extra long ones are too expensive”.

The HAFAD member of staff who deals with social care and direct payments spoke of the many cases where "existing care packages [have been] reduced even though support needs are the same" and how this was "having a massive impact on people's day to day lives, causing debt, stress, and a worsening of mental and physical health". A particular problem was that in 2011, the local council had cut the hourly rate used for direct payments, so that people received less money to pay for their care even if they were assessed as needing the same number of hours. He spoke of the distress caused when disabled people had to tell someone who may have been working with them for years that they would either have to take a pay cut or no longer work for them. This was also an issue raised in the focus groups where people talked of how the council's actions had led to "a complete lack of choice and control over one's care”.

Difficulties in getting housing adaptations were also raised in the focus group and by some questionnaire respondents. People reported further additional costs or need to go into debt due to changes in provision of adaptations by local authorities. A focus group participant spoke of how "any equipment or adaptations needed in home due to impairment are no longer covered. I was told to take out a loan to pay for them", while a questionnaire respondent wrote of her difficulty getting access to adaptations:

“Cut backs to social services and to local authorities in general combined to mean that arranging the home adaptations I need have taken at least 2 years of grueling meetings, letters and phone calls, and still the adaptations are not yet underway”.

Both focus group participants and questionnaire respondents gave many examples of the cumulative impact of reductions in local services and their increasing cost. There was a general feeling that reducing expenditure was increasingly the focus for local services and that people's actual care needs were secondary and in some cases not taken into account. The HAFAD staff member interviewed felt this was a result of a "year on year budget focus with no real impact assessment of how all cuts and changes in services and provisions will affect people".

4.4 Advice, information and advocacy

A key message from the focus groups and questionnaires was the need for more advice, information and advocacy in the context of both benefits and local services.

Several people said how hard it was to get comprehensive information about what their benefit entitlements were and what they needed to do to claim them: as one man said, "the names of benefits have changed and it's quite obtuse and confusing as to one's entitlements, and there is no single place to go to for directions as to what each individual should get for help". Some also reported how draining trying to access this information can be: “Constant phoning and chasing wears you down”, while another

wrote, “I’m drowning in paperwork and admin bureaucracy, doped up on morphine and can’t even get out of bed”.

Even where there might be people or places that can give advice the cuts to these services make it hard to access them: “I contacted a group to help me fill in the ESA and DLA forms but their waiting times were so long it exceeded the due date of when the form had to be handed in.”

Another respondent wrote that: “CAB inadequate resources make them less accessible and less effective than needed - also they are unable to help with many things now due to pressure of work, and are also unable to get the levels of skills claimants need them to have. No other source of help with claims in this geographic area”. This respondent also wrote of difficulty in accessing representation and support for appeals and tribunals and this was an issue raised by others. People spoke of being “terrified” of having to appeal without support and some mentioned how the loss of legal aid for benefits tribunals is also making appealing decisions a lot harder.

The need for advice and advocacy was also apparent in the context of ensuring that individuals were not unfairly penalised, for example where Job Centre personnel tried to wrongly apply conditions attached to a single parent’s entitlement to ESA when she was placed in the Work Related Activity Group: “At present I’m not required to undertake work related activity because I’m a lone parent with a child under 5. However, my local Jobcentre were not aware of this DWP regulation exempting me. I have had to battle

with them to prove the DWP regulations, otherwise they were threatening to sanction my benefits for not undertaking work related activity”.

4.5 Social attitudes

Neither the online questionnaire, nor the information schedule used for the first focus group, asked about social attitudes but this was an issue raised spontaneously by both sets of respondents.

Twenty-five percent (18 out of 72) of respondents to the online questionnaire mentioned experiences of negative attitudes towards them as disabled people. These responses were mainly prompted by the question “Are there any other government policies which have had an impact on your life since 2010?”. Negative experiences ranged from abuse from strangers to changes in attitudes amongst friends and acquaintances

One woman wrote: “I have started to be verbally abused in the street by strangers in relation to my disability, which hadn't happened to me before, although it has been visible for at least four years”. Another stated: “I've had someone I was passing in a cafe doorway tell me that if I can walk even a couple of steps I shouldn't be using a wheelchair!”

Respondents wrote of how experience of abuse made them reluctant to leave home. One wrote “have been out of house once in 2012 and was shouted at in street for 'getting money from govt for that' (ie my disability/wheelchair)” while one woman said: “The

government's policies and the lies they sell to the media have made me scared to go out as hate crimes have increased. I was attacked and called a scrounger last time".

People also reported how relationships with neighbours and friends have been affected: "I'm now frightened to speak to neighbours I have known for years, because of the DWP press releases relating to disabled people as scroungers and fraudsters". One person wrote of having been investigated by the DWP "in response to a neighbour's complaint that there was nothing wrong with me so have been questioned like a criminal even though they already had the answers to the questions they asked, I have had to have several medicals and I am so scared of it all happening again I am suicidal".

Some spoke of being scared of those that live around them or who they have considered friends and one woman spoke about being afraid even when she was in her home: "I worry that I'm being filmed through the windows. This is all making my mental health problems worse".

A number of people wrote that they felt that the government and media are fueling negative attitudes towards disabled people with one man stating: "I see more and more headlines about benefit scroungers, which I know to be false". Another respondent spoke about the impact of this on her mental health and perception of herself: "The effect may be insidious but is nonetheless very real – social isolation and a tendency to internalise a guilt I should not feel, as I am ill through no fault of my own and worked

tremendously hard throughout the first twelve years of having MS [multiple sclerosis]”.

Similar experiences and feelings were expressed by those taking part in the larger focus group. Again, this was an issue which was raised spontaneously rather than in response to a specific question concerning social attitudes. Analysis of the discussion revealed that, of 21 participants, 18 spoke about negative attitudes towards them as disabled people. Of these only one said he had not experienced any increase in such experiences. The remaining 17 felt that, for example, their experiences represented "a sea change for disabled people", and that "Suddenly you've become a scrounger and made to feel guilty" and are "treated like scum". The consequences of this included people finding they were "questioning myself and if I was indeed 'really' disabled, despite it being obvious that I am" and "a constant feeling of paranoia" and a general impact on mental health with people talking about "living in a constant state of terror".

4.6 What should disabled people's organisations be doing?

Although the questionnaire respondents were probably more likely than the general disabled population to be involved in some way in disability politics and activism (because of the way the questionnaire was disseminated), 73 per cent of respondents were not in contact with a DPO and 60 per cent were not aware of one in their local area. The questionnaire sought views on how a local DPO might help disabled individuals and how they should respond to current policy changes affecting disabled people.

One of the key issues mentioned by respondents was how DPO's could or should be addressing the previously mentioned negative social attitudes towards disabled people. As one person wrote, DPOs should “Work with charities, think tanks and academics, and - most of all – the media to shift public attitudes which are turning toxic”. There was a general feeling that DPOs should raise awareness amongst the general public to increase understanding and help change current negative social attitudes: “They could focus on getting non- Disabled people to know what is fact and what is govt/media misinformation, to understand what we are facing and to campaign with us in challenging the govt agenda.”

Some respondents also talked about the need to bring people together to campaign against specific policies: “Organisations can help to collectivise the response and organise protests e.g. against Atos, against cuts and make links with trade unions and other organisations”. There was a great sense of anger and injustice amongst those at the focus groups and a feeling that they really needed to express and direct this at someone who was involved in government or council decision making.

Others wrote of the need to “collect evidence of impact of cuts”, and how “At a national level, DPOs must fight against these inequitable cuts and bring them to the attention of as many people as possible in the wider community”. One person wrote that DPOs should “Get people to care a bit more, raise profile about the human misery this is causing, try & shock the general population into treating disabled people with kindness & respect”.

As mentioned above, access to advice and information was an issue raised by a number of respondents and this was an area that it was felt DPO's could and should be helping with. They "could publicise info on process of applying for community care - no info available from council at all, I delayed applying for a long while because I was anxious and didn't know what to expect".

Advocacy is also an area people identified as being important and which could be provided by DPOs: "it's important to offer support in claiming benefits and the appeal process, and when care is not being provided or is being incorrectly charged".

A few people mentioned the importance of DPOs enabling connections with other local organisations that can offer support and information: "More Information, advice and guidance work with the legal aid, law centre or CAB in collaboration" and "They could introduce me to other services, help me make friends, be less isolated and advise me on accessible shops/hairdressers/dentists in my area as it's hard to find those by yourself." Another said she would like a local DPO to "give me benefits advice but also support on accessing training".

Respondents to both the questionnaire and those at both focus groups spoke about the importance of peer support. One woman said she "would like to meet and talk with other terminally ill cancer patients", while another wrote "Involvement in a DPO can help counter isolation and promote a more positive self image". Those attending the larger focus group also expressed how the

experience of the focus group was a positive one and one that made them want more contact with people who were dealing with similar issues to themselves.

The discussion about DPO's in both focus groups centered on how important HAFAD was to people. One woman spoke about how scared and worried she had been but once she was in contact with HAFAD "from that moment on I knew I'd be OK". Another woman asked "what would we do without HAFAD?. People felt that the important things about HAFAD were that the staff were all "approachable" and "understood how to" work with and support them. That they were "impartial" and "have no hidden agenda", that they "genuinely care" and "give a damn".

Finally one of the questionnaire respondents said many DPO's lacked adequate funding and that "In the absence of this funding your question is perhaps the wrong way round – What can Disabled people do to support DPO's...There are Disabled people who out there who have well paid jobs or pensions, who have influence (directly or indirectly), who are not engaging because the cuts won't have such a big impact on them. If they were actively involved in, and supporting DPO work it could make a very big difference".

Chapter 5: Conclusion

This research highlighted important issues relating to the impact of cuts and changes in benefits and services, as well as indicating what disabled people want from DPOs. It also provided some important lessons for HAFAD concerning potential future research.

5.1 Research findings

5.1.1 Impact on disabled people

Although many of the cuts and changes are yet to come, those already implemented are having a significant impact. There is a cumulative impact in that people are facing not just a cut in their income but also a reduction in support services and/or an increase in charges. Disabled people are more likely to already be living in poverty: when the additional costs of disability are factored in, 47 per cent of households with a disabled person are living below the poverty line (Grant, Wood, 2010, pg 20). Many research participants described the fragility of their financial situation, and how the loss or reduction of benefit income – even if it was then restored – could create significant and lasting financial, physical and emotional problems.

Respondents felt that the general climate associated with the changes had resulted in increased negative attitudes towards them as disabled people. Some had experienced abuse while others feared it. Generally, there was a feeling of injustice and often humiliation associated with assessments for benefits.

There was fear amongst those awaiting a Work Capability Assessment, and also fear of coming changes, in particular the replacement of DLA with PIP. One woman, relying on her DLA to fund the help she needs, facing the prospect of a Work Capability Assessment, summed it up: “I’m really fearful about what is going to happen to me in the near future”.

5.1.2 Key messages for DPOs

Amongst the questionnaire respondents there was a low awareness of local DPOs and few people had been in contact with them.

There was a great need for advice, advocacy and information services amongst respondents. Such services would need to be up-to-date with the rapidly changing benefit system and provide information and access to advice in a range of formats and ways in order to be accessible to disabled people.

Those that were in contact with a DPO were very worried about how the cuts might impact on the DPO. This was particularly noticeable in the focus group where all participants expressed how important HAFAD was to them and a concern about how they would cope without the organisation’s support.

Some respondents also felt that DPOs needed to challenge negative social attitudes towards disabled people and disability benefits. It was felt they could do this by providing information

which countered the messages given by government and the media about the disabled population. This would suggest that a campaigning element of DPOs is important and that simply focusing on delivering services is not enough. This has been an increasing issue for DPOs as they have found funders can be hostile towards any campaigning or activism the DPO engages in (Inclusion London, 2012, pg 21). In some cases DPOs are forging links with independent campaign groups in the area to try and 'get around' this tension (Inclusion London, 2012, pg 22).

5.2 Implications for further research to be carried out by HAFAD:

The focus groups were a useful method for enabling research participants to determine the research agenda. For example, it was the discussion amongst the participants (rather than the questions written by the researcher) which highlighted the importance of changes in social attitudes.

The focus group method also enabled more detailed understanding of the interaction of different policies and cumulative impact, and the fragile nature of people's financial situations. Both issues are important for enabling a local DPO like HAFAD to understand the type of expertise required to deliver the advice, information and advocacy services that disabled people require in these difficult times.

Social media was a useful way of eliciting responses to a questionnaire, but this method of recruiting respondents has

limitations in terms of reaching out to all sections of the disabled population. Nevertheless, as long as these limitations are recognised it may be worth pursuing as a low-cost way of recruiting research participants.

Ideally, HAFAD needs to gather quantitative data in order to know how representative these experiences are. Such information is needed not only for campaigning purposes but also in order to plan for adequate advice, information and advocacy services.

However, it may well be that existing quantitative data about the local disabled population, together with DWP data and estimates on those impacted by benefit changes, may enable projections to be made as to how many people are affected by the experiences revealed by qualitative research data. Such a possibility will need to be pursued when drawing up the proposal for the larger piece of research.

Bibliography

Barnes, C. (1992) *Qualitative Research: valuable or irrelevant?* Disability, Handicap and Society, Vol. 7, Issue 2, pp 115-124

Barnes, C. (2001) *Emancipatory' Disability Research: project or process?* Public Lecture at City Chambers, Glasgow, on 24 October 2001. <http://www.leeds.ac.uk/disability-studies/archiveuk/Barnes/glasgow%20lecture.pdf>

Barnes, C. (2008) An Ethical Agenda in Disability Research: rhetoric or reality? In Mertens, D. M. and Ginsberg P. E. (eds.) 2008: *The Handbook of Social Research Ethics*. London: Sage, pp. 458-473.

Barnes, C. and Mercer, G. (1997) *Breaking the Mould? An Introduction to Doing Disability Research*. In: Barnes, C. and Mercer, G. (Eds.) *Doing Disability Research*. Leeds: The Disability Press

Barnes, C. and Sheldon, A. (2007) "Emancipatory" Disability Research and Special Educational Needs, in Florian L., (ed) *The Sage Handbook of Special Education*, London: Sage, pp. 233-246.

Barnes, H, Sissons, P. and Stevens, H. (2010) *Employment and Support Allowance: Findings from a face to face survey of customers*, Department for Work and Pensions. <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep707.pdf>

Barton, L. (1999) Developing an Emancipatory Research Agenda: Possibilities and Dilemmas, In: P.Clough & L.Barton (eds) *Articulating with Difficulty: Research voices in inclusive education*. London, Sage, pp. 29-39

BBC, 2012. *Reviewer of fitness to work benefit test to stand down* (<http://www.bbc.co.uk/news/uk-politics-19046447>)

Browne, K. (2005), *Snowball sampling: using social networks to research non-heterosexual women*, *International Journal of Social Research Methodology*, Vol. 8, Issue 1. pp. 47-60.

Citizens Advice Bureau, (2010), *Not working: CAB evidence on the work capability assessment*,
http://www.citizensadvice.org.uk/aboutus/aboutus/not_working.htm

Citizens Advice Bureau, (2012a), *Right First Time: An indicative study of the accuracy of ESA work capability assessment reports*,
http://www.citizensadvice.org.uk/right_first_time

Citizens Advice Bureau, (2012b), Citizens Advice response to DWP consultation on work capability assessment: accounting for the effects of cancer treatments. Citizens Advice Bureau.

Citizens Advice Bureau and Macmillan Support, n.d. *Failed by the System: Why the Employment and Support Allowance isn't working for people with cancer*.
<http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Benefits/FailedByTheSystemReport.pdf>

Community Care, (2009), *Employment and support allowance slammed on first birthday*.
<http://www.communitycare.co.uk/Articles/27/10/2009/112983/employment-and-support-allowance-slammed-on-first-birthday.htm>

Crowther, N. (2012), 'What the disability hate crime statistics really reveal is huge disparities in the performance of police authorities across the UK' <http://www.neilcrowtherconsulting.com/blog/what-the-disability-hate-crime-statistics-really-reveal-is-huge-disparities-in-the-performance-of-police-authorities-across-the-uk>

Daily Telegraph, (2012), *500,000 to lose disability benefit*, 13 May,
<http://www.telegraph.co.uk/news/politics/9263453/500000-to-lose-disability-benefit.html>

Department for Work and Pensions, (2011). *Time limit Contributory Employment and Support Allowance to one year for those in the Work Related Activity Group*,
<http://www.parliament.uk/documents/impact-assessments/IA11-022AF.pdf>

Department for Work and Pensions, (2012a). *Employment and Support Allowance: Outcomes of Work Capability Assessments – New Claims*. Quarterly Official Statistics Bulletin July 2012.

http://research.dwp.gov.uk/asd/workingage/esa_wca/esa_wca_jul2012.pdf

Department for Work and Pensions, (2012b). *Employment and Support Allowance – Incapacity Benefit Reassessments: Outcomes of Work Capability Assessments*. Quarterly Official Statistics Bulletin March 2012.

http://research.dwp.gov.uk/asd/workingage/esa_ibr/esa_ibr_mar12.pdf

Department for Work and Pensions, (2012c). *Public consultation on the future of the Independent Living Fund*. Department for Work and Pensions.

Edwards, C. 2012. *The Austerity War and the Impoverishment of Disabled People*,

<http://documents.ncodp.org.uk/news/3%20September%202012%20The%20Austerity%20War%20and%20the%20impoverishment%20of%20disabled%20people.pdf>

Emmel, N, Hughes, K, Greenhalgh, and Sales, A. (2007). *Developing Methodological Strategies to recruit and research socially excluded groups: Methods Briefing 19*, University of Leeds

<http://www.ccsr.ac.uk/methods/publications/documents/Emmel.pdf>

Evans, J. (2011). 'Rights and Social Inclusion or Cuts and Social Exclusion', Paper presented to European Day Conference, *Europe's Way out of the Crisis: The Disability Rights Perspective*, Brussels, December 1st. " <http://www.leeds.ac.uk/disability-studies/archiveuk/evans/The%20impact%20of%20the%20austerity%20measures%20on%20disabled%20people%20in%20Europe.pdf>

False Economy, (2012a). 'Lost care hours after assessment', 21 August. <http://falseeconomy.org.uk/cuts/testimony/lost-care-hours-after-reassessment>

False Economy, (2012b). 'Increases in care charges', 23 March. <http://falseeconomy.org.uk/cuts/testimony/increases-in-care-charges>

False Economy, (2012c). '*Newcastle city council - introduction of caps on high-cost care packages*', 28 March.

<http://falseeconomy.org.uk/cuts/item/newcastle-city-council-introduction-of-caps-on-high-cost-care-packages>

Flick, U. (2006). *An Introduction to Qualitative Research* (3rd Ed.). London, Sage Publications

Franklin, K. and Marsh, S. (2011). *The Benefits Scandal*, Soundings, Vol. 49, pp.43-56

French, S. (1994) *Researching disability*. In French, S. (ed.) *On Equal Terms: Working with disabled people*, Oxford: Butterworth Heinemann

Gore, E. and Parckar, G. (2009). *Disability and the Downturn*, Leonard Cheshire Foundation.

Guardian, (2012a). '*Cap on care at home could drive under-65s into institutions*' 17 July.

<http://www.guardian.co.uk/society/2012/jul/17/social-care-disability>

Guardian, (2012b). '*Disability hate crime is at its highest since records began*' 14th August.

<http://www.guardian.co.uk/news/datablog/2012/aug/14/disability-hate-crime-increase-reported-incidents-data>

Harrington, M. (2010). *An independent review of the Work Capability Assessment*, The Stationery Office.

<http://www.dwp.gov.uk/docs/wca-review-2010.pdf>

Harrington, M. (2011). *An independent review of the Work Capability Assessment: Year Two*, The Stationery Office

<http://www.dwp.gov.uk/docs/wca-review-2011.pdf>

Hunt, P. (1981), *Settling Accounts with the Parasite People: A critique of "A Life Apart" by E.J. Miller and G.V. Gwynne*, Disability Challenge, vol. 1, pp. 37-50. Available at:

<http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>

Inclusion London (2012), *A Matter of Survival: Funding experiences of London's Deaf and disabled peoples organisations*

and implications for disability equality.

<http://www.inclusionlondon.co.uk/a-matter-of-survival>

Joint Committee on Human Rights, (2012). Implementation of the Right of Disabled People to Independent Living

<http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/25702.htm>

Kitzinger, J., (1994), *The Methodology of Focus Groups - the Importance of Interaction between Research Participants*, Sociology of Health & Illness, Vol. 16, Issue 1, pp 103-121

Labour Force Survey, Quarter 2, 2011

Learning Disability Coalition, (2011), *Social care - the continuing crisis: from the perspective of local authorities in England.*

<http://www.learningdisabilitycoalition.org.uk/download/Social%20Care%20-%20The%20Continuing%20Crisis.pdf>

Local Government News, (2012), 'ADASS warns of £890m budget cuts' 14th June.

<http://www.localgov.co.uk/index.cfm?method=news.detail&id=105919>

Mercer, G. (2004), From Critique to Practice: emancipatory disability research, in Barnes, C. and Mercer, G. (eds) *Implementing the Social Model of Disability: Theory and Research*. Leeds: The Disability Press, pp. 118-137.

Morgan, D. L. (1997), *Focus groups as qualitative research* (2nd ed.). Thousand Oaks, CA: Sage

Morgan, G. (2012), *Benefits After the Act: The future of means-tested benefits after the Welfare Reform Act 2012*, Ferret Information Systems.

Morris, J. (1992), Personal and Political: a feminist perspective on *researching physical disability*, Disability, Handicap and Society, Vol. 7, Issue 2, pp 157-66.

NCVO Civil Society Almanac (n.d), *How are public sector spending cuts affecting the voluntary sector.* <http://data.ncvo->

vol.org.uk/almanac/voluntary-sector/income-in-focus/how-are-public-sector-spending-cuts-affecting-the-voluntary-sector/

Office for National Statistics, (2010), *Life Opportunities Survey: Interim results 2009/10*, Office for National Statistics.

<http://www.ons.gov.uk/ons/rel/los/life-opportunities-survey/life-opportunities-survey/index.html>

Office for National Statistics, (2012), *Statistical Bulletin: Internet Access Quarterly Update 2012 Q2*.

<http://www.ons.gov.uk/ons/rel/rdit2/internet-access-quarterly-update/2012-q2/stb-internet-access-2012-q2.html>

Oliver, M. (1992) *Changing the social relations of research production*, *Disability, Handicap and Society*, Vol. 7, Issue 2, pp 101-114.

Oliver, M. (1997), *Emancipatory Research: Realistic Goal or Impossible Dream*, in C. Barnes and G. Mercer, (eds), *Doing Disability Research*. Leeds: The Disability Press, pp 15-31.

Palmer, (2007), *Disabled People, Poverty and the Labour Market*, New Policy Institute.

<http://www.poverty.org.uk/reports/disability.pdf>

Park, A, Clery, E, Curtice, J, Phillips, M. Utting, D. (2012), *British Social Attitudes 29*. National Centre for Social Research.

http://www.bsa-29.natcen.ac.uk/media/13421/bsa29_full_report.pdf

Punch, K. F. (2005), *Introduction to Social Research: Quantitative and Qualitative Approaches* (2nd ed). London: Sage.

Punch, M. (1994), *Politics and ethics in qualitative research*, in N.K. Denzin and Y.S. Lincoln, (eds), *Handbook of qualitative research*. Newbery Park, CA: Sage.

Rutherford, J. (2007), *New Labour, the market state, and the end of welfare*, *Soundings*, Vol 36, pp. 40-55.

Scope, (2008), *Getting away with murder*, Scope.
http://www.scope.org.uk/sites/default/files/pdfs/Campaigns_policy/Scope_Hate_Crime_Report.pdf

Silverman, D. (2006), *Interpreting Qualitative Data (3rd edn.)*. London: Sage

Sissons, P, Barnes, H. and Stevens, H. (2011), *Routes onto Employment and Support Allowance*, Department for Work and Pensions, <http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

Social Research Association, (2003), *Ethical Guidelines*. London, SRA <http://the-sra.org.uk/wp-content/uploads/ethics03.pdf>

Sparrow, M, (2012), *Chris Grayling, you've made me financially as well as physically disabled*, The Guardian, April 29
<http://www.guardian.co.uk/commentisfree/2012/apr/29/chris-grayling-made-me-financially-physically-disabled>

Stone, E. and Priestley, M. (1996), *Parasites, pawns and partners: disability research and the role of non-disabled researchers*, British Journal of Sociology, Vol. 47, Issue 4, pp 699-716

Strathclyde Centre for Disability Research and Glasgow Media Unit, (2012), *Bad news for disabled people: How the newspapers are reporting disability*,
http://www.inclusionlondon.co.uk/domains/inclusionlondon.co.uk/local/media/downloads/bad_news_for_disabled_people_pdf.pdf

Stevenson, M (2010), Flexible and Responsive Research: Developing Rights-Based Emancipatory Disability Research Methodology in Collaboration with Young Adults with Down Syndrome, Australian Social Work, Vol. 63, Issue 1, pp 35-50

Swain J. And French S. (2004), *Researching Together: A participatory approach*. <http://www.leeds.ac.uk/disability-studies/archiveuk/French/A%20PARTICIPATORY%20APPROACH%20TO%20RESEARCH.pdf>

Wade, D.T. and Halligan, P.W. (2004), *Do biomedical models of illness make for good healthcare systems?*, British Medical Journal, Volume 329, December, pp.1398-1401

Wilkinson, S. (1998), *Focus groups in feminist research: Power, interaction and the co-construction of meaning*, Women's Studies International Forum, (1998), Vol 21, Issue 1, pp 111-125.

Wood, C. and Grant, E., (2010), *Destination Unknown*, Demos.
<http://www.demos.co.uk/publications/destinationunknowndisability>

Wood, C. (2012), *Destination Unknown, Summer 2012*, Demos.
http://www.demos.co.uk/files/Destination_Unknown_Summer_2012_-_web.pdf?1340294386

Zarb, G. (1992), *On the Road to Damascus: First steps towards changing the relations of research production*, Disability, Handicap and Society, Vol 7, Issue 2, pp 125 - 38.

APPENDIX ONE: ONLINE QUESTIONNAIRE

Impact of cuts and policy changes on disabled people and how disabled people's organisations can respond

This is short survey in which you do not have to answer any questions you do not wish to and, dependent on the length of your answers, should take 5-15 minutes to complete. All answers are confidential and will be used as part of a MA dissertation which aims to gather a sample of disabled people's experiences of the current cuts and changes to disability related services and benefits, and how local disabled people's organisations can best respond. All data collected is anonymous and please feel free to contact me at ss10rm@leed.ac.uk if you have any queries. Thank you very much for taking time to fill this in.

1. How old are you?

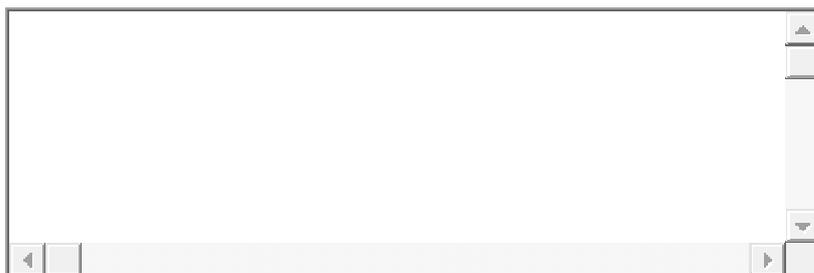
(please only tick one box)

- under 18
- 18-24
- 25-39
- 40-64
- 65+

2. What gender do you identify as?

- Man
- Woman
- Other
- Prefer not to say

3. What county or borough do you live in?



4. How would you describe your impairment/disability?

- Physical
- Mental Health
- Learning difficulty
- Sensory: vision/hearing
- chronic illness
- multiple
- Other:

5. How did you hear about this survey?



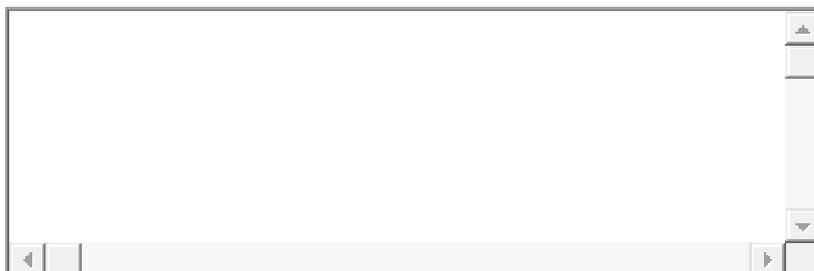
6. Are you currently or have you recently (within the last two years) been in receipt of benefits or local authority support? This can be directly related to your impairment, e.g DLA/ESA/Direct Payments/Community Care or Independent Living Fund Grants/Access to Work etc, or not directly related, e.g housing benefit/income support/child benefits

- yes
- no

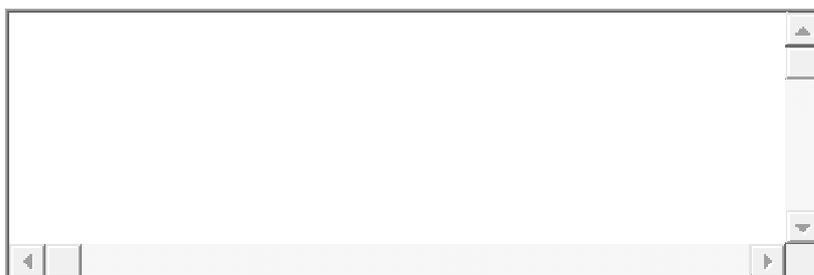
7. Have there been changes to any benefits you receive since 2010? If so what were these changes?



8. Have there been any changes to any local authority support you receive since 2010? If so what were these changes? These might be community care services (home carers, day centres, meals on wheels, etc) or direct payments or personal budgets designed to cover these.

A large, empty rectangular text input box with a light gray border. It features a vertical scrollbar on the right side and horizontal scrollbars at the bottom, indicating it is a multi-line text area.

9. What impact have these changes had on your life?

A large, empty rectangular text input box with a light gray border. It features a vertical scrollbar on the right side and horizontal scrollbars at the bottom, indicating it is a multi-line text area.

10. Are there any other government policies which have had an impact on your life since 2010? If so please describe these.

A large, empty rectangular text input box with a light gray border. It features a vertical scrollbar on the right side and horizontal scrollbars at the bottom, indicating it is a multi-line text area.

11. Are you aware of a local Disabled People's Organisation (DPO) in your area?(a local DPO is an organisation based within your local borough, city, or region which is run and controlled by disabled people. For further info see: <http://www.disabilitylib.org.uk/disabled-peoples-organisations-dpos>)

- yes
- no

12. Are you in contact with a local Disabled People's Organisation (DPO) in your area?

- yes
- no

13. What could a local Disabled People's Organisation do to most help you in the context of the changes you have experienced?



14. Is there anything else you'd like to say about the impact of cuts on disabled people and how disabled people's organisations might best respond?



Appendix Two : Analysis of Questionnaire Respondents

Table 1: Source of questionnaire respondents

Source	Number	Percentage
Twitter	36	50
Facebook	15	21
Discussion list	17	24
Other	4	5
Total	72	100

Table 2: Age distribution of respondents to online questionnaire

Age	Numbers	Percentages
Under 18	3	4
18-24	3	4
25-39	23	32
40-64	42	58
65+	1	1

Table 3: Answers to the question - 'How would you describe your impairment/disability?'

Impairment/disability Numbers		Percentages
Physical	17	24
Mental health	15	21
Learning difficulty	0	0
Chronic illness	5	7
Multiple	26	36
Other	8	11

Appendix 3: Focus Group Topic Guide

Research Question One: The impact of the current cuts in services and benefits on disabled people

Have you experienced any changes to benefits you receive in the last two years?

Are these related to out of work benefits or additional costs?

Have you experienced the WCA?

Have you experienced any changes to social care you receive in the last two years?

Have you seen a reduction in either your care package or what level of 'need' you are assessed as requiring?

What impact has any changes in these had on your day to day life? Including any changes to services which are not directly related to disability.

Prompts: transport, hospitals, advice, advocacy, legal aid, other benefits.

Research Question Two: What disabled people want from local DPOs in this context

How has HAFAD supported you during this time?

What do you think an organisation like HAFAD can do to support people?

Prompts: Advocacy, form filling, information

Appendix 4: HAFAD Staff Interviews Topic Guide

How many service users do you have contact with in the average week?

And in what context/what does your job involve in terms of direct contact with service users?

How would you say they have been impacted by:

- a) cuts and changes in adult social care?
- b) cuts and changes in benefits?

What support have you been able to offer them?

What else do you think HAFAD should be doing to support people?

Prompts: Delivering services, campaigning against cuts.