

Barriers and Perceptions

A research project exploring the experiences of
Disabled people seeking employment

MAIN REPORT

Peter Millington – October 2007

Funded by

Birmingham City Council's ESF (European Social Fund)

Co-financing programme



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Foreword

by Louise Simmons

Chief Executive of the Birmingham Disability Resource Centre

Here at the Birmingham Disability Resource Centre we have been providing employment support services to disabled people since the early 1990s. During this time we have observed many fundamental changes in society's response to disability and to disabled people, especially in the area of employment.

Twenty years ago, disabled people had much lower expectations when it came to seeking or retaining employment. Before 1995 there was no official protection from discrimination when it came to securing and sustaining employment. Even though there was a government registration scheme which obliged larger organisations to employ a set quota of disabled employees, the voluntary code was never enforced and was operated on the good will of committed companies and agencies.

Significant change began to take place after the passing of the Disability Discrimination Act 1995, as more and more sections of legislation came into force and the expectations of disabled people started to rise for the first time in history. The long-term aspirations of disabled people no longer had to be based on the choice between a life spent on welfare benefits or a career spent doing mundane work with no prospects of promotion.

Alongside the gradual introduction of anti-discrimination legislation and the rising expectations of disabled people, there has been an increase in the support and advice services on offer to both disabled employees and their prospective and current employers. The development of Disability Equality Training, diversity training and access auditing have helped more and more employers to recognise the importance, not just of employing disabled people but of making their whole organisation accessible and inclusive to all.

The support and information available to disabled people themselves has increased during this period with a greater number of training and support agencies and schemes.

Yet according to research findings published by the Department of Work and Pensions in 2007 (*Report number 416—Persistent Employment Disadvantage*), disabled people continue to have high unemployment rates and are less likely to enter employment once out than other non-employed people. The report says “the employment penalty” (defined as the ‘sources of disadvantage’) “faced by the disabled population has increased substantially since the 1970s”.

With so many factors looking bright, greater numbers of disabled people saying they would *like* to work; more employers being convinced of the benefits of becoming accessible and inclusive; more training and support

agencies offering advice and guidance; and greater attention to the issues from the government, something is clearly still standing in the way of progress.

In May 2006 the Birmingham Disability Resource Centre received funding from Birmingham City Council and the European Social Fund to carry out research into the barriers and perceptions which may still be preventing large numbers of disabled people from gaining employment or engaging in other types of economic activity.

Is it a case of a person's personal incapacity, the restrictions of their impairment / medical condition that prevent them from being able to work?

From our own experience of working with and for both disabled people and employers here at the Birmingham Disability Resource Centre, providing benefit advice to individuals, supporting disabled people looking for work and training businesses, we know that the barriers are more complex and are not exclusively centred around the individual.

During this fascinating piece of research we have listened to disabled people and support workers from across the city of Birmingham who represent a wide range of communities, types of disability and other factors and have recorded their views, experiences and perceptions about the barriers that continue to add to (in the terminology of the Department of Work and Pensions) – 'the employment penalty faced by disabled people'.

There are a number of key findings and recommendations at the end of our research. In our final section there is an underlying point for us about connectivity and looking at the whole picture with implications about linking services, replacing restrictions with incentives, supporting both employees and employers, addressing social and procedural barriers as well as supporting individuals who are looking for or considering work.

We hope that our findings and recommendations contain tangible ideas that can lead to practical activities.

Thank you to everyone who has supported and participated in our research project. Thanks to our research facilitator Pete Millington and to our funders, Birmingham City Council and the European Social Fund.

Louise Simmons—Chief Executive

Introduction

In May 2006 the Birmingham Disability Resource Centre launched a research project around the perceptions and barriers to employment faced by disabled people and those in receipt of incapacity benefit. The research was funded by Birmingham City Council's European Social Fund Co-financing 2005-2007 (3 Measure 2.2) and its aim was to make recommendations for the design of future programmes and complementary employment support services for disabled people and those in receipt of incapacity benefit, with the objective of achieving greater impact and effectiveness.

The research was conducted through three distinct phases with a fourth element, desk research, being ongoing throughout the other phases:

- 1st Questionnaire Phase
- Action Research Phase
- 2nd Questionnaire & Focus Groups

One of the main proposed outcomes of the research was to increase knowledge of the perceptions and barriers experienced by disabled people, relevant to the Birmingham situation. Another was to increase the understanding of those service models which are most effective in increasing economic activity and reducing unemployment amongst disabled people.

Our research therefore proposes new service delivery models aimed at meeting needs and minimising or removing identified barriers. The research assesses the effectiveness of different service models in overcoming barriers to employment through the perceptions and experiences of disabled people in Birmingham.

The research adds value to other recent research and highlights areas for improvement of service delivery in order to achieve greater impact and effectiveness.

Methodology

The research project was carried out from May 2006 until August 2007 with a report-writing phase in September and October 2007. It was an Action Research project and its methodology was therefore designed to gain qualitative data. An initial questionnaire phase of the project was designed to identify issues which could be explored in greater depth within the action research phase.

Desk Research

The desk research phase involved an in-depth analysis of information and existing research around disability and employment.

Questionnaire Phase 1

The Questionnaire Phase ran from June 2006 until November 2006. Our aim was to gain a combination of quantitative data through the use of closed questions and qualitative data through the use of open-ended questions. 156 people took part in the questionnaire phase. Group interviews were also held during this phase.

Action Research Phase

The Action Research Phase focussed on 25 people who were asked to explain and reflect on specific barriers and / or perceptions which made it difficult for them, either now or in the past, to engage with training and employment opportunities. Participants were asked to keep reflective diaries. Recordings included taped interviews, email recordings, one-to-one meetings, self-reflective diaries and group meetings.

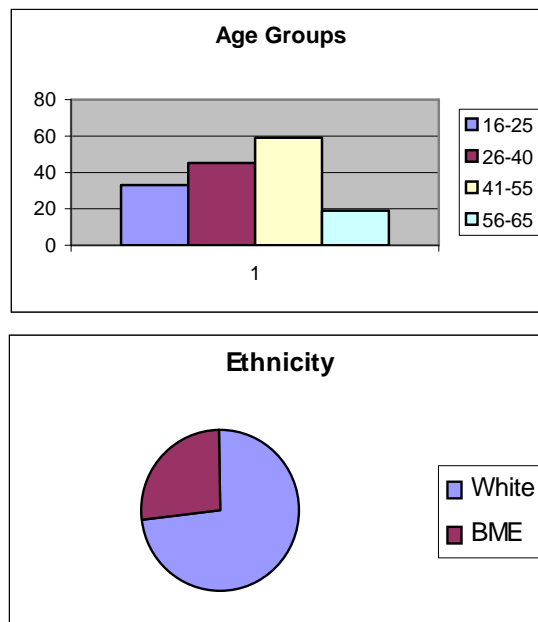
Questionnaire 2 and Focus Groups

A second phase of Questionnaires was carried out between May to the end of July 2007 and 3 Focus Groups were held which were attended by service providers.

The people who took part in the research

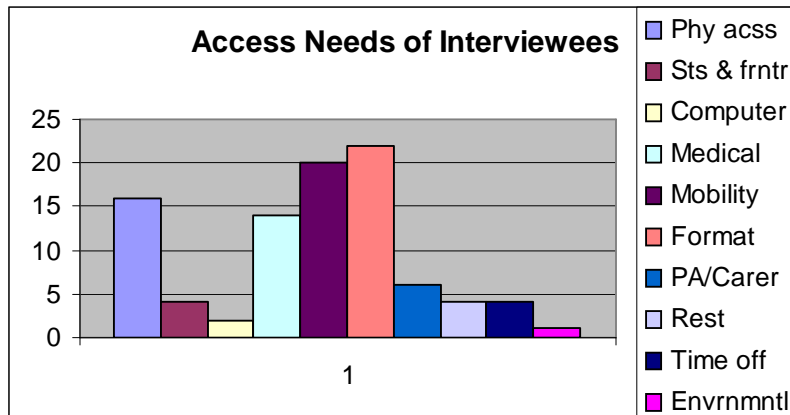
200 disabled people and service providers from Birmingham took part in the research. 156 people took part in the Phase 1 Questionnaire, of these people 70 were male (45%) and 86 (55%) were female.

21% of the Questionnaire participants came from the 15-25 year age range, 29% from the 26-40 age group, 38% from the 41-55 age group and 12% from the 56-65 age range. 113 (72.5%) of the respondents described their ethnicity as white, whilst 43 (27.5%) described their ethnicity as being from a black minority ethnic community (BME).



Respondents were asked a broad question about their access needs relating to their impairment. Many individuals said they had more than one impairment and our proportionate figures reflect this. The highest number of people had health and medical conditions (25%), followed by people with mobility difficulties (22%). Other impairments represented in our Questionnaire responses included people with hearing impairment (14%), people with visual impairment (8%), people with learning disability (12%) and people with mental health issues (8%).

The same question provided information about individual access needs which also helped us to identify some broad groups based on individual experience. It should be added that not everyone answered this question and that many people told us they had two or more types of access need. The highest numbers of people said they need information in accessible formats (24%), people needing support with personal mobility and transport (2.5%), people needing physical access to buildings (17%) and people who sometimes require access to medical support (15%).



Findings from the Phase 1 Questionnaire

Our interviewees were asked to tell us about their past experiences in relation to the support they have received in terms of training, job searching and employment. 71% of our respondents were in receipt of incapacity benefit. A further 25% were in receipt of another benefit such as Job Seekers Allowance and / or Income Support with only 4% being in some form of employment at the moment.

In the comments box many people told us that they had been without employment for several years, below is a sample of the responses:

“I left school at aged 16 and have had no paid employment since then – 6 years ago”

“I have not worked for over 20 years”

“I have been on Incapacity Benefit for 12 years”

“I used to own my own company but closed it down in 1997”

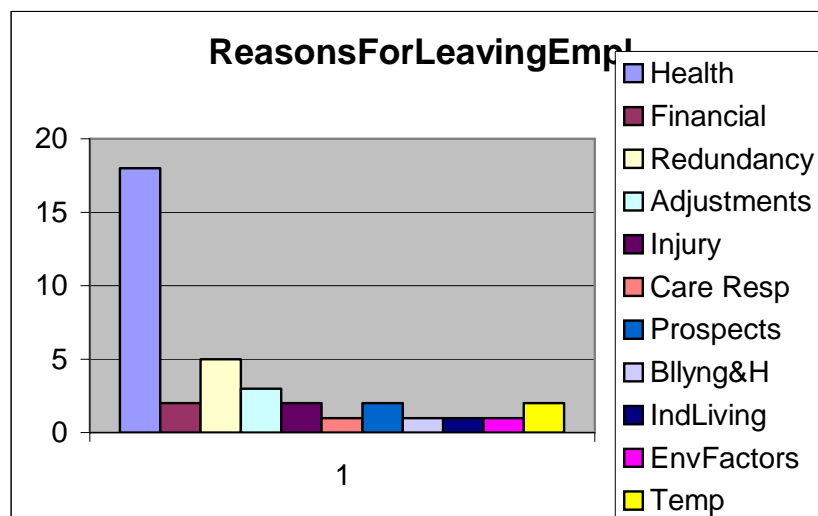
Respondents were asked if they are taking part in permitted earnings, voluntary work or anything similar. 64% said that they are not currently engaged in any work related activity, 12.5% were doing voluntary work, 1% were involved in education courses and 12.5% were currently on training courses.

Amongst the people engaged in training, these fell broadly into four types of short term training including numeracy and literacy related courses (33%), information technology - mainly basic computer skills (27%), English language training courses (27%) and NVQ / work experience based courses (13%).

Interviewees told us about the work they have done in the past, either as a disabled person or before they became disabled. The spread of types of employment was very broad with voluntary sector employment (17%), health

& care (15%) and retail (9.5%) having the highest numbers. Other fields of employment were represented in equally spread numbers and included administration, manufacturing, utilities, training & development, catering, banks & finance, cleaning, tourism, computers (ICT), education, social enterprise, journalism, leisure and construction. Whilst the disabled people who took part in our research represent a wide cross-section of employment experience, there was a notable absence in our sample of people with a background in more prestige jobs such as business directorship, higher management, etc.

Our respondents were asked, “Why did you stop doing this work?” and the larger majority (47.5%) said it was due to health reasons. A range of other factors were identified such as redundancy (13%), insufficient adjustments in the workplace (8%), injury (5%) and lack of prospects in the workplace (5%).



A sample of comments to this section of the Questionnaire include:

“I left my job due to health reasons and gave up my voluntary work due to finance reasons”

“Ill health – I retired due to an inability to maintain safety with handling materials. I was a teacher and there was a risk I may have injured a child if I continued work”

“I need occasional but very substantial hospital admissions for essential treatment. This has affected my entire confidence level. Once I put this information on job applications or go for interviews, I am rejected because employers don’t want to employ someone who spends a lot of time in hospital”

“Excessive exposure to electro magnetic fields in the college environment. I was without work for a total of six years”

“I was only on a fixed term contract, it was a case of “thank you very much for helping us – here’s a reference”

Respondents were asked whether they believe that their period of not working is directly related to being a disabled person. With the exception of one respondent to this question, everybody replied “yes” and provided a wide variety of qualitative observations about their experience and perceptions as to why they have not been able to re-enter employment, here is a sample of the responses:

“Firstly, concerns about access and feeling that my disability was a liability to them and secondly having time off for hospital appointments”

“In most respects, a lack of self confidence due to previous unemployment. A lack of support (flexible policies, difficulties in interviews sometimes)”

“I don’t think the problem is with my impairment, I think it is to do with the intolerance of employers. They look at your CV or your application and when they see you are visually impaired they just don’t bother. I also have problems filling out application forms because they are always in written text”

“Factories won’t listen to access and health and safety concerns, they just won’t take you on. My previous employer made technical adjustments to accommodate my disability but when I was made redundant it was impossible to expect prospective employers to make the same level of adjustments”

“I think I will have problems finding work as a disabled person because of the existence of barriers, just living is more problematic, so the search for work is more tiring and more stressful. Fatigue is a big problem for me. It’s fine if you have your life sorted – if everything works as it should then fine, but a disabled person needs a more empathetic employer. The current government wants more people in work – however what about more work being done with employers to make them aware of disabled people’s lives?”

Respondents were asked whether they found incapacity related benefits adequate to live on and the majority of people (74%) said “no”. The additional responses to this question indicate that many people find the benefit system complicated and inadequate, with a common response being that individuals would prefer to earn their income, even in a partial way. Here is a sample of comments:

“No. I did not receive Incapacity benefit because when I was made redundant they did not classify me as being disabled. So I signed on for the first time in my life. I wanted to earn money. Benefits were certainly not adequate to live on”

“For 12 years of my life I have been having treatments for my back. The last 6 months I have experienced a deterioration with increasingly chronic pain, so I see my future on incapacity benefit and doing less than 12 hours a week, but I don’t want to sit in my house looking at the 4 walls”

“I don’t find benefits enough to live on, so that’s why it’s a good job that my wife works and brings in more income”

“I had incapacity status – but I did not have enough NI stamps for the benefit. I was not given the chance, but anything would have been better than nothing”

Perceptions about being on welfare benefits were further explored with questions that asked respondents (a) how they felt being in receipt of incapacity related benefits and (b) do they think that the description of being ‘incapable’ is an accurate one to describe their personal circumstances. Taken together, the two questions provide enlightening information about the attitudes and perceptions of our respondents. Whilst some respondents are either reconciled and/or indifferent to the potential stigma of being officially labelled as ‘incapable’, many others express their unhappiness with and resentment of such negative terminology. Below is a selection of responses, which include comments on both the practical implications of being on benefits as well as perceptions about the stigma attached to the term ‘incapacity’:

“I don’t have much choice because if I start working for instance, I couldn’t claim things like housing benefit. It sounds crazy but most people are better off not working. In a perfect world, yes get a job, get paid, bank it, start a family and have kids, just like “normal” people ...society’s expectations. But life forces me to do this because taking the risk is far too big to take. That’s why there is such a big gap because these people say to disabled people “why can’t you do this or do that or go to work?” Even doing voluntary work at the library is the first time anyone has ever taken me on”

“It gives me an opportunity to stand back and look at what jobs I am capable of doing”

“It’s not enough to live on. I can’t do full time work. A full day at college nearly killed me. If I can come off benefits and find guaranteed work without it having to be full time, it might be worth it. But I can’t take the risk”

“That’s a hard one, the word “incapable”, people with a disability still have a brain - people can do work in flexible circumstances”

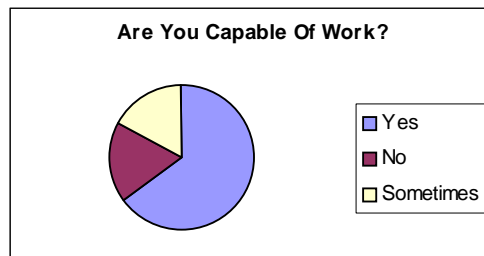
“Been on benefits so long it would be good to have a job but I’m worried that I won’t be able to sustain it and could be worse off”

“I am on the bottom rung of the ladder and the barriers to employment started before I even reached the ladder”

“No, I think it’s not being incapable. It’s a case of not being ready – not having a chance”

“Of course not. The use of language is important here. Many people could work given appropriate support. The label of incapacity sends out the wrong messages. It’s very ‘either / or’ when there should be mixed provision”

64% of the interviewees said that they are capable of doing some form of work given the right support and reasonable adjustments with a further 17% saying that they could do occasional work depending on factors such as their own pain levels and the flexibility of their employer. 18% said they cannot do any work at the moment.



Respondents provided more qualitative responses about the work they could do if barriers were overcome:

“I would consider permitted earnings but have spent 6 months looking at walls and writing poetry to fill the time. If I had a sitting job I could use my brain mentally for about 2 days or something”

“Yes but I was a long term attendee of a day centre, I needed positive experiences to build up my independence”

“We need more companies who understand disability. I worked for a very positive company who were willing to change my job role when my condition changed. So I went from the deli to the clothes department and when my hands had problems the supervisor put me on hanging clothes, then someone put me on jewellery. It shows their flexibility”

“Journalism – I would need a PA to help communication, take notes, support if I got tired. Suitable access and toilet facilities for my chair. Support with transport to and from work. Feeling comfortable in the workplace – keeping up with peers”

“Doing voluntary work gives me a chance to do what I want to do whilst having time to sort out my diabetes and not feeling under pressure if I have time off. It was great when I had to have 3 weeks off recently but

then came back and people said “it’s ok” and not “where have you been?”

“Flexibility is a crucial thing, meaning that when things are being done in a traditional way there has to be some flexibility, e.g. travelling into work, reserved parking that is available. There are a lot of things in our lives that may be an inconvenience for someone else but for a disabled person become a major battle. My ethos is that the world doesn’t owe me a living - I’m an opportunist. But fatigue may force me to give up”

“I would need transport to and from home to the place of work. I need admin support because my writing is not good. I need IT support and funding for ‘business style’ clothes”

“Work from home in my purpose built office or ask for clerical assistance in the workplace to limit my exposure to technology. Or work in a room away from the technology. Or have my own purpose built office in the workplace. Or job share. There are many alternatives, it just needs creative thinking”

Having been asked about some of the factors which prevent them from working, respondents were asked about the factors which motivate them or are most likely to motivate them to seek work. Having more money is very important (57%) and quite important (40%) to the majority of respondents. Having a career is also very important to high numbers of the respondents (60%).

Working as a means of having something to do, in other words the occupational benefits of work, was important but not as important as money or having a career - 42% of people thought it was very important to work as a means of having something to do with their time and an equal number thought it was quite important.

In terms of the affects of external pressure from other people as a motivating factor in seeking work, respondents do not feel it is effective or useful. 80% of respondents said that pressure from their friends, peers and relatives was not an influencing factor on them, similarly 83% of respondents were not affected by pressure from government agencies, whilst 67% of respondents were not influenced by media stories about the number of people claiming incapacity related benefits or negative stereotyping.

A higher number of respondents said that encouragement from support agencies had a very important influence on them (30%) compared to pressure (3.5%). Fear of losing benefits has some affect on people - 20% say it is a very important motivating factor, whereas larger numbers think it is either quite important or not important (40% each).

Very few of the respondents have begun looking for work because their medical condition or impairment has significantly altered (7%) although a further 33% say it has some bearing on their quest for employment.

Other factors which influence why a person is motivated to start looking for employment, included the following sample of comments:

“It is important to have a sense of worth, well being and confidence”

“I have no dreams because of my lack of qualifications. Other people are afraid of my skin condition so I am very isolated at home. I feel some pressure from the Jobcentre to look for work. With no job I don't get exercise. I would like a job to get me fit and healthy again”

“I am desperate for normality. My circle of friends has changed since becoming ill. A lot of my friends are now disabled people.”

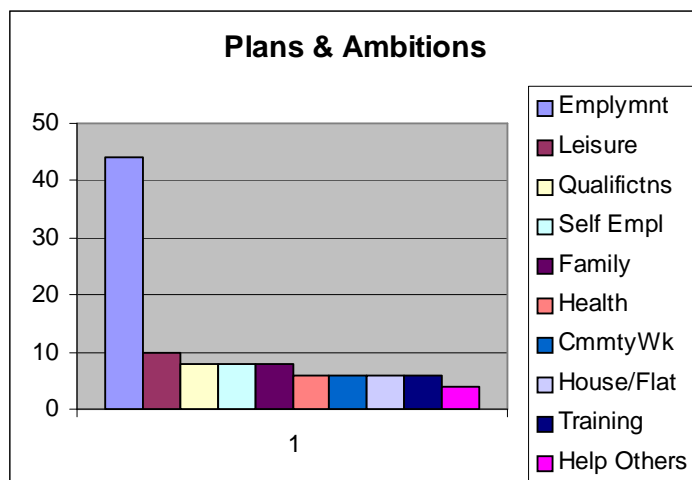
“When you're ill you tend to sleep a lot because of tiredness. Being out of pain and thinking straight becomes rare. I get angry sometimes. I try to push the boundaries – firstly it was physical such as gym work to keep my body going. I even bought a dog for exercise. It's difficult for my friends to appreciate the pain I experience, especially male peers”

“I want to be valued”

Support to find employment

Section 3 of the questionnaire was designed to gather data about the types of support available to disabled job seekers in Birmingham, to explore the perceptions of disabled people about this support and the agencies that provide it and to collect examples of good and bad practice.

Firstly we asked respondents to tell us about their own plans and ambitions in the next 2 years. By far the largest singular proportion of people said that getting a job was their highest priority (38%). Other common ambitions centred around participation in leisure related activities (9%), gaining qualifications (7%), specific plans around becoming self employed (7%), plans relating to family life (7%), improvements or stabilisation of individual health issues (5%), aspirations of engaging in community and voluntary work (5%), resolving housing issues or achieving better accommodation (5%) and engaging in training courses (5%)



Here are some of the comments provided by the respondents:

“I would like to be in work and getting on with my life, making new friends.”

“I would love to help people like myself in giving them confidence. They would give me something as well towards my own confidence - even if I only get through to one person, that would be very rewarding to me”

“To stay in employment and hope that my health doesn’t deteriorate”

“My plans are to complete re-training and hopefully find part time work in the areas I’m working towards. Don’t know if I’ll ever work full time again because of my diabetes and back problems”

“My plans are to get a little job and get some certificates from college”

“To be more assertive.”

“I would like a good job to get me fit and healthy again”

“Do interesting things. I don’t expect to work but want to give back something to society”

“Be less reclusive than I am now. I know I can’t ever do sport but I am also restricted in other ways and would like to start living life more without restrictions.”

“I’d like to take the children to do things, for example go to the pictures to watch a film. I feel socially affected”

“Self employment via the internet. I had a laptop but can’t use the internet. A few things in place to create my own working environment would help my future”

We asked respondents if they were getting support from local employment and/or training support agencies in achieving their goals. The responses indicated a wide range of local and national agencies including the following (many of these agencies were mentioned more than once, many several times):

AB Plus	Action For Blind People
Allens Croft Project	Ashyana Project
B:Zen	Bham Chamber of Commerce
Birmingham City Council	Bham Disability Resrce Centre
Bham Services for Deaf People (BID)	Building Health
BVSC	C.P. Midlands
Centre For Inclusive Living	Chapman Road Day Centre
Community Options	Connexions
Employment Preparation Team	Employment Zone
ENTA	Jericho
Jobcentre Plus	Heart Charity – Yew Tree
Learn Direct	Learning and Skills Council
Leonard Cheshire	Mencap
New Outlook	Phoenix
Portland College	Queen Alexandra College
Rathbone Birmingham	Remploy
RNIB	RNID
Selly Oak – Dyslexia learning centre	Shaw Trust
Solihull College	Strawberry Studio
University of Central England	Work Directions
Working Links	

Respondents were assured that we will not give the names of the agencies alongside their comments in order to ensure their own confidentiality and that of external individuals, thereby also enabling the respondent to be open, forthright and honest in their opinions and perceptions.

Overall, the satisfaction level of respondents about employment support agencies in Birmingham is divided, with 43% of respondents feeling that the services they have used understand their needs in respect to disability and access, whilst 39% feel that the agency they have been in contact with does not understand their needs. 7% of respondents felt partly satisfied and 11% did not know.

In terms of whether the agency is pointing them in the direction that they want to go in, 37% expressed satisfaction, 37% expressed dissatisfaction, 15% said it is partly the case and 11% saying they didn't know.

In terms of an expression of overall satisfaction, once again opinion is sharply divided into similar measures with 48% being satisfied with the service they receive, whilst 41% are not satisfied and 4% being quite satisfied.

The comments provided alongside these views identify examples of both good and not so good practice in supporting disabled job seekers. This is a sample:

“When I was volunteering at (*community group*), I took a Clait course and passed because I was supported with everything I did by the centre. I was supported in my course and the work I was doing voluntarily”

“Retrospectively, the (*government officer*) was very useful because they offered several items and I chose (*residential college*). Later on I was put in touch with (*employment trust*) who got me a position in voluntary work and did do a follow-up. I was on their books for 3 months before getting a position then I got a job, once a month I had a visit from my support worker which I found very useful”

“I have done a mentoring course and some other training. Also doing English and Maths at College and a counselling course. I found the mentoring course very useful – I think it is a good idea for disabled people to receive mentoring. I have found it useful to study English and Maths as these are recognised qualifications”

“I get support and encouragement from the (*job club*). I am doing voluntary work at the same centre and benefit from support and advice from the workers here who can speak from their own experience. This is important because people are in the same boat as me so I can discuss my problems with them. It’s better that people can share their problems with someone who has had similar experience”

“No training or support. I need something to do with my time because I can contribute to my household economy”

“No. I wouldn’t go to statutory authorities for support because they are gate keepers of resources and you have to push them to get anything. There can be a close comparison drawn between different types of statutory agency. Contact should be made every few months with clients so that the door is kept open. But the pressure on them is that they have to get someone into a job to get them off their books”

“I feel I was born 30 years too early because opportunities weren’t there when I was younger”

“I trained as an Information Officer with (*advice agency*) with the help of a Community Champions grant. I worked as a volunteer youth worker and now I’m a member of various health / council networks”

“Yes, (*community organisation*) is the support agency I go to - at present they are helping me to get on an aromatherapy course”

“I did a pre vocational course which was very useful”

“None. When you are on long-term incapacity / income support they leave you alone. Would be frustrated with courses as I know more than the people delivering them”

“I get phone calls from agencies but the help is less than satisfactory”

“All I get is help from someone at the day centre at (*day centre*) where I have a key worker”

“Support agency has been good because they make me understand I’m not a cabbage”

“In terms of training support, (*charity*) run a Job Club and various courses aimed at equipping people with new skills. They also have internet access and are looking towards getting more funding for ICT training”

“Some of the biggest problems faced by service users include language and cultural barriers, but also issues such as not having credit to make phone calls or spare income to travel on public transport”

“Many of the African women who use the centre have child care responsibilities, so issues around proper maternity, nutrition and health care tend to take priority. Social isolation can also be a major barrier, so the centre tries to encourage a thriving calendar of social events”

“A voluntary placement learning new skills and work experience has been invaluable”

“I went to the (*employment support agency*) via a social worker. But since 2004 I have had 3 years of total isolation”

“Employment opportunities use barriers as a way of making excuses – there is no chance to achieve the opportunities”

“My voluntary work and also the Clait course – they were both useful to me, it gave me confidence in myself with computers, using the phones, talking to people with confidence”

“The (*statutory agency*) was useful because of the options I was offered. The problem is not many people on IB go into the (*agency*), so how do they come into contact with the (*support worker*). Only people on JSA benefit from the service”

“(*Charity*) helped me most because the girl did my CV and looks out for jobs and has written off for jobs. They are always in touch with you”

“(Charity) helped me with filling forms. It’s personal and practical support that I need. They don’t just dump you – they follow it up”

“Can’t really comment as there isn’t anyone helping, I’ve been doing it on my own”

“I could and should get more qualifications but would it increase my current capacity? Not at the moment. I don’t need practical support at the moment. I get emotional support from family and friends.”

“Guidance and counselling support. Encouragement in assertiveness from my boyfriend’s parents”

“The support was useful to the extent that the person tried to get me into jobs but it was the employer who was stopping me getting the jobs. Even when they are offered financial help from Access To Work, they are still frightened”

Respondents were asked to provide more details about specific access barriers which influence whether they are successful in finding a job.

64% of interviewees said that physical access to and around buildings was important to them. 20% of our interviewees have a need for support related to sensory impairment whilst 62% said that communication issues were important.

72% of our interviewees said that personal support and assistance is important. 57% of the interviewees said that having an understanding support worker is very important when trying to obtain or sustain work. Having support with accessible equipment is important to 54% of the interviewees with 51% saying that support to access and use ICT equipment is of high importance.

On the question of flexibility, respondents told us that this is one of the most important single issues which will help them to be successful in gaining employment, with 73% of people saying that flexibility is very important to them and a further 17% saying it is quite important.

Similar responses were recorded for the desire to have supportive colleagues in a new workplace or training environment, with a convincing 76% saying this was very important to them and 16% saying it was quite important.

Similar levels of importance were put on having positive procedures in place that support disabled people’s rights, with 77% saying it was very important and 13% quite important. Finally on the question of the importance of perceptions, it seems that people consider their own perceptions (57% very important) when entering a new situation as being of higher importance than the perceptions of other people (42% very important).

Our questionnaire respondents added the following additional comments about issues which will influence how successful they will be at gaining employment in the future (sample of comments):

“Income considerations”

“I need support to access ICT, as long as there is JAWS reading & speech software. I need visual support. I can do most work as long as I receive clear instructions and have reading support. I am fine if I am in a place that is blind friendly”

“Once familiar with work situations I am ok. Need text enlarging software. Sometimes I am affected by other people’s perceptions of me”

“I need personal support outside when I am travelling in my work, not necessarily inside. Flexibility in the workplace is vital. It’s about having a relationship with your personal assistant based on give and take. Negotiation”

“If companies discriminate through their procedures then they should be asked to change any policies that exclude disabled people. If the policy says that workers must wear a tie but can’t wear a tie then the policy should be scrapped. I believe that when you encourage staff to use their ability – they will do the job. It’s a balancing act”

“My own perceptions and other people’s perceptions are actually linked together. Individual perceptions are linked to other people’s perceptions. I get treated differently by different people. I find that when you show you can give and take then you build up good relationships with other people”

“For a disabled person, their basic needs can be enormous. Direct Payments are very important to many disabled people. Common sense is required by Jobcentre officers to understand the lives of disabled people”

“I need business experience not personal assistance. Equipment and IT are dependent on the job but I would expect a company to provide these as required. I expect supportive colleagues anyway.”

“If I couldn’t do the job on my own without a support worker, I wouldn’t want to bother. If you can do it, you can do it, you can’t expect employers to go out of their way. I’d expect supportive colleagues whether or not I am a disabled person”

Issues For Action Research

In the fourth and final section of the Questionnaire, respondents were asked to identify specific barriers and perceptions which could be explored in a more

in-depth way through action research. People were asked which issues they most commonly experienced in their lives. Amongst the most commonly experienced issues were:

- Poor and inaccessible design of every day objects
- People not listening or trying to understand what someone is saying
- People not being treated as an equal
- People not being respected by others
- People feel that others do not understand the impact of their impairment
- People wishing they had an advocate or mentor
- Not understanding jargon
- People feel that others are afraid or intolerant of their impairment
- People have problems gaining access into buildings
- Public transport is frequently inaccessible
- Difficult to get information in a chosen format
- Others do not accept someone is disabled
- People feel they are treated as a medical condition, not a person

Below are additional comments about issues where people feel that more research is required:

“Lack of qualifications, skills and experience – if you are on Incapacity Benefit and not going to Jobcentre, you don’t know what’s there – so people need information on opportunities. For certain jobs I might need the right equipment but may not know the equipment needed until I’m in the situation – so information about Access to Work is important. I also need some flexibility in terms of access and travel arrangements”

“Some people can’t see my impairment, people look at me as if I’m ok”

“I experienced a situation at college where I had to explain to people in detail my medical condition. They understand at the time but then it’s having to explain about the affects of diabetes. But then, it’s not a perfect world so it’s sometimes necessary to explain that I may have a hyper reaction so people will understand what is happening to me”

“I can only use taxis, not buses. I am worried about losing my incapacity benefit. I can do transcription of audio to text but can’t understand Asian languages for transcription. I have a lot of independent living needs such as I need things like talking appliances such as microwave”

“Inability to stand, sit and bend over long periods – nothing can be done for my current condition. I have had continual limited financial support, but no encouragement to seek employment. No information or advice – more one to one advice & support regarding financial position”

“People listen but don’t act on instructions. Fortunately I am confident and articulate and I demand respect. I don’t automatically blame

people for their poor communication as I don't consider it their fault, there are degrees of understanding and people may have been conditioned by past experience. When it comes to jargon it is about having the confidence to challenge"

"My difficulty is explaining my own point of view to others. I find it difficult to express myself so I can be easily misunderstood"

"Generally other people understand my disability because I don't stand for any nonsense, but it could be a problem if I were more sensitive. My colleagues are not told that I am on permitted work – this would cause potential for jealousy from my colleagues who might treat me differently. Sometimes I hear passing comments from colleagues in conversation, people look at you and can't accept my category of disability. This is the problem with a hidden disability. I don't always think the person accepts if they can't see the disability, i.e. a wheelchair. Sometimes I feel like I'm just a medical condition – but not in the workplace"

"I would like more contact with someone in the role of a disability support officer because I have fluctuating days and so it would be useful to chat to someone sometimes, personnel don't always have the time. I can't travel on buses as it causes me pain and anxiety and I can only drive short distances in a car"

"I find objects are usually an issue when I least expect it. Before my impairment I used to be very precise but now I find I am clumsy. I am treated differently by my peers. I find that my social life has suffered because I can no longer afford to go into pubs, this means that your social group changes. I don't expect people to understand the impact of my impairment but the experience has broadened my own understanding of other disabled people"

"I feel advocacy is important. On the question of jargon in language, I used to read a lot of journals for the purposes of my work, so I understand the languages of different professions and areas of expertise, such as law, science, medicine, engineering, computers, etc. I think there is a justified need for jargon"

"I hide my disability as much as I can. It's no one else's business and I don't expect them to understand"

"Transport concerns and problems. We need to improve the attitudes of taxi firms and give them training. Demand a more reliable service and honesty. Subsidise more TX1 and TX2 taxis through the government.

"Lack of a P.A. I need funding, need to get on well with the person and need someone to help with the speed of doing things"

“Lack of accessible buildings – knock them down and start again.
Provision of automatic doors, ramps, etc”

“Pain, affects my mobility on some days. Public transport isn’t actually inaccessible, but it can be difficult to use if you are experiencing pain and restricted mobility. I find that the Benefits people don’t believe or accept people with pain related conditions, getting incapacity benefit is a rigmarole”

“There are Access to Work issues, applications take 6 months to assess and process and during that time the disabled person and the employer don’t know if they’ll get the help”

“You are still faced with all these negative perceptions of the employers. They think it will cost a lot of money to adapt their premises or that the disabled person will have a lot of time off sick, but research shows otherwise”

“Public transport, especially buses. The drivers are not very considerate and are always in a hurry. How can you go to a job if you can not even get from A to B”

Respondents were asked if they can expand on any of the barriers and perceptions identified in the Questionnaire by suggesting what could or should be done about the barriers and who should make the required changes:

“Access, sometimes having a disability, transport. Make access to buildings better, ramps, lifts, etc, make employers take on more disabled people and do checks to make sure it’s been met, help with transport where needed”

“Employers approach to disabilities – employment agencies and Jobcentres should do something about this”

“Just to give people with disabilities a chance, understanding and most of all confidence in themselves – we can do something about it - ourselves and the agencies”

“Information about options. The government should address this but the problem is that people don’t trust governments so a more independent agency, such as a group dedicated to supporting people on incapacity benefit should be given state funding to do it. They need to be seen as independent to avoid creating distrust”

“I would like to change the perception that everyone on incapacity benefit doesn’t want to work. I believe that people want to work but don’t have the skills and experience to find work. People may know what they want to do but the government won’t fund it”

“Disability should be catered for in the workplace in terms of accessible amenities, i.e. ramps and toilets. Inflexibility in the workplace is also an issue in terms of not being able to find suitable work. Management are often too inflexible to realise that there may be more suitable positions for associates (workers) in the workplace. Either you do the job they specify or you don't do it at all”

“Women were better catered for than disabled people in terms of equal opportunities and flexibility. There were double standards when women get more equal opportunities than men. The unions should look after everyone equally”

“To educate people in the side effects of diabetes. To develop a way of explaining to people that hyper and hypo reactions have medical causes and are not due to the person being violent or having mental health problems. Changing perceptions which have an adverse affect on me, because I'm a large framed person people presume I'm going to be violent”

“I have a lack of confidence, I often feel that I don't believe I can do a job. To get around this I need more training and experience. Money is also a barrier to me”

“No advice or information. Need more one to one advice. Information about financial positions – possibly myself in liaison with local employment agency. I need to investigate the possibilities more thoroughly”

“Attitudes towards people with mental health problems and learning disabilities – more awareness is required amongst trainers, employers and agencies”

“Making people more aware that just because you have a disability, you can still do things. More awareness is needed on how disabilities operate. There needs to be more awareness work – an opportunity to explain our views about what you want and how disabled people can be helped to work”

“What I notice going up the parade near where I live is that people respond differently to me when I am in an electric wheelchair to when I am in a manual chair. Motorised chairs seem to cause people to move out of the way. It causes a bigger impact”

“How to be more assertive and explaining myself to others. Training – assertiveness”

“Experience will always work more than qualifications in a workplace but you need to convince people to take you on”

“Interview techniques and CV support”

“Get some training done. Attend Job club – make notes and posters”

“I’d like to be a manager”

“A college that said I wasn’t qualified, so I went away and got qualified, I went back to the college and this time they admitted it was inaccessible”

“All colleges should be made accessible (perhaps things are better now)”

“Low awareness of companies about disability. When a colleague is on the sick the department manager just runs them through the “Return To Work” but for a disabled person there is a more long-winded process in terms of linking periods of sickness. The “Return to Work” process should be based on a scale that takes into account changes in a person’s condition, because they are aware of your disability they should give you more flexibility as you can’t predict when your condition will flare up”

“If a company employs someone with disability they should be on a different scale to take this into account”

“Lack of access to IT. Access to the internet from a low economic position. Mentoring for disabled people wishing to start off in business. Finding out about future research opportunities”

“Involve more disabled people’s inclusion in the process. Maybe mentoring disabled people in the direction of self employment”

“Transport – licensing committee, scrutiny panel, BCC, individuals, community groups, highlight issues, challenge attitudes, fight for what should already be there. Working currently with (*local agency*) to do this”

“Attitudes across the board – everyday situations. We should sack people on phones – (*department*) etc. I would like to gain employment in government to communicate my own ideas and needs”

“Becoming self employed”

“Difficulty with impairment related face-to-face communication – more attention to communication needs of sensory impaired people in general and disability equality training for staff”

“Access technology and ICT – more thorough understanding of IT access needs”

“Lack of flexibility in transport – much greater spending and improvement on public transport”

“Access to buildings (DDA 95) I feel not much has changed in 10 years. Maybe in the public sector but not in the private sector, it’s still very poor in terms of access to buildings. I think we need to be raising awareness”

“Getting Direct Payments”

“Employers perceptions about employees taking prolonged periods of time off for hospital treatment”

“Disabled people on schemes are excess to requirement – the perception that you are on a scheme not a valued worker”

“People having low expectations of disabled people”

“More one to one centred support – help to get disabled people rewarding activities such as voluntary work”

“Permanent employment at the end of training schemes”

“Employers ignorance – employers need to be more open to other ways of working / ask the employee how they think the task / job could be worked”

“Agencies criteria / based on funding – agencies need to be given more flexibility, they are often restricted by too prescriptive funding criteria”

“Assessment criteria - government strategy needs to change, decision makers should consider the wider picture and be prepared to adjust assessment criteria and their own schemes to enable more people to access the workplace”

“No end to my placement. More support to develop and move on from work placements and training schemes, permanent employment at the end of schemes”

“Low expectations about what I can do from other people. Low self confidence and need help to build up my independence”

“Work habits / employers ignorance – the government and councils should promote homework”

“That every work function has to be carried out in an office base – government departments should join in the promotion of this ethos. I want to keep sowing the seed. Apply for positions and ask if they can be worked from home”

“Single parent – working and parenting. I have found it difficult to stick to training courses – I was doing a course at the Women’s Academy”

“Lack of understanding about my disability. Prejudice and stereotyping. Travel difficulties especially Access to Work. Difficulties with colleagues re: fear of me having a fit”

“There needs to be more education:- employers must have disability training. Access to Work should be more transparent”

“Mobility, speech and hearing – should be systems in place, management awareness and talks to understand so everyone can be aware”.

“My own self confidence is a barrier. I would like to be able to talk to people. I can start doing this through work experience and voluntary work”

“Lack of confidence when meeting new people. It’s part of my Asperger’s Syndrome which not many people know about. I can push through when I need to. I need to get to know more people to gain self-confidence. Explaining my condition to other people helps, for instance the PA at (*youth employment agency*) has written a letter to attach to my CV which explains what Asperger’s Syndrome is.”

“The (*employment agency*) website is very difficult to navigate as a visually impaired person. Also I don’t think ICT is the answer to all problems for disabled people – it’s not good to work from home and shop from home, we need to interact to stop ourselves becoming isolated. It affects your confidence a great deal – you have to get out and make friends”

“Applying online for a job with (*do-it-yourself company*) I had to go through a long process of taking a psychometric test online which took about one hour. On the same day (*DIY store*) sent a pre-printed standardised letter turning me down on the basis of the test results alone. There was no reference to the job itself or my C.V. skills and experience. I think companies like (*DIY store*) should not use such a computerised system of assessing people for employment with no regard to the actual job being applied for or the CV of the person applying. This needs to be brought to the attention of (*DIY store*) and other agencies”

Phase 2: Action Research Case Studies

In the Action Research phase we developed Case Studies focussed on 25 people who had expressed an interest in this phase of the project during the Phase 1 Questionnaires. Please note that whilst 25 people took part in the action research phase, in some interviews there were more than one person, so we therefore have a total of 19 case studies below. All real names have been changed in the following case studies:

Case Study 1

Andy and Alice are disabled members of staff from a disability services centre in Birmingham. Andy is the manager of the centre and Alice is a support worker. The centre is a relatively new centre run by disabled people and exclusively employs disabled people. They provide advice and support around independent living issues.

At the moment they have around 54 disabled people using the service. One of their priorities is supporting people who wish to leave either residential accommodation, institutional care or living with parents or family members. The centre helps people find suitable accommodation and put in place support services. They also assist people to acquire financial support such as the Independent Living Fund and Direct Payments.

As well as offering their own ideas and personal experiences, Andy and Alice offered additional case studies based on clients who use their service at the moment.

Alex

Alex is a male aged 31 who has been unable to get past the hurdles of independent living and is in the midst of 'a struggle' to get Direct Payments. He has also had his Independent Living Fund cancelled. Alex has a substantial need for personal assistance and without financial support for his basic living needs he is finding it impossible even to get on the bottom rung of the ladder.

Anne

Anne is a 35-year-old woman who needs occasional but sometimes substantial hospital admissions for essential treatment. She has found that this has affected her entire confidence level in terms of trying to seek employment. She does not have confidence in presenting herself as an individual seeking employment. This has become a huge hurdle for Anne. She feels that once she puts this information into a job application form or goes for an interview, she will be rejected because an employer will not want to employ someone who spends a lot of time in hospital. Andy and Alice described that this is a well-founded fear because in their experience many employers will reject candidates for this reason but will justify their decision as a case of another candidate being more suitable.

Arthur

Arthur has been participating in a 'training scheme' for a number of years. They entered the scheme believing that they would gain permanent employment at the end of it, but have been there ever since. They have expressed that it is a 'dead-end job' and that there is no end to the placement. Because they are seen as 'the person on the scheme' they also frequently suffer insults from work colleagues.

April

April is a disabled woman in her late twenties. She has had a more positive experience and was a student on a pre-vocational training course run by a disability charity. Alice described how April has come a long way in terms of personal development and this has increased her general level of independence. Her starting point was as a long-term attendee of a day centre.

General Discussion

In addition to the four case studies above, Andy and Alice shared a great deal of their own personal views on the issues addressed within the remit of the research project. These are some of their own views and responses:

"Training should be about identifying people's skills, so training for someone coming off incapacity benefits should be designed to give them a taster and an opportunity to develop confidence"

"Training is often geared around presentation stuff for the training provider itself. There is no analysis of what disabled people actually need in terms of their own training needs. People have to fit into the box that is provided by someone else".

"Resources spent on job introductory schemes would be better spent where there is a real job at the end of it. It is all based on supernumerary schemes, where people only stay for 12 months. But how many people move on from the schemes? How much support do they get to move into long term employment?"

"It's about a person's personal development, not just about them doing a work placement for 12 months and being dropped"

"The disabled people we work with face barriers from day one because there are no equal opportunities for them. First it's segregated education, then they're not offered training, they don't get the opportunity to get higher education qualifications. Because they don't get education, training and qualifications, they don't sell well on paper or at interviews. This then means they don't get work experience. So there is not a fair starting point and the circle goes on and on"

“Even when you find an employer who wants to start a disabled person, it’s very hard for all sorts of reasons. It’s ok if it’s a basic admin job but any job that requires flexibility from the employee becomes more difficult, a lot of jobs these days involve multi tasking and disabled people can’t always do that. Someone that employs a disabled person then expects them to do this and sets them up to fail”

“You are still faced with all these negative perceptions of the employers. They think it will cost a lot of money to adapt their premises or that the disabled person will have a lot of time off sick, but research shows otherwise”

“There are Access to Work issues, applications take 6 months to assess and process and during that time the disabled person and the employer don’t know if they’ll get the help”

“Disabled people are reluctant to phone and ask about access issues during the recruitment stage because they are afraid they will be seen as incapable. The DDA hasn’t changed much in respect to these issues because it’s about perceptions”

“The benefits trap is a big barrier for disabled people, there is a risk in getting a job, people are scared about losing their benefits, this is the argument for a social wage or social income where you have a sliding scale and people don’t have to make one leap from benefit to work”

“What does an employer want done? Is it necessary for the employee to turn up to the workplace to do that job? Does the person need to be there to do the job? What is the cost benefit? Can they be somewhere else? By enabling someone to work from home for instance, will there be savings on other costs such as travel, lighting, the environment?”

“People may say supervision is an issue for people working at home, but targets can be set for someone in the home place, you measure performance by whether the targets are met, reaching those targets doesn’t have to be done in the workplace”

“What about telematics? Our concepts of work have to change. If there are accessibility issues in the workplace, it may be possible to do the job from home instead. Is the work a 9-5 job? What if someone needs to sleep in the daytime but can work at nighttime? There are cost savings for the employer here”

“Many executive officers work through hand held technology these days, why can’t disabled people work like this? The research is all there, disabled people and employment, labour market research is all online, why isn’t it being acted on?”

“There is a conceptual barrier that disabled people will not make good employees. When you say “well what about this person or that

person?” the response is that disabled people who succeed are one-offs. But this is not true”

“A lot of the barriers are related to the question of perceptions, for instance the levels of severity, the idea that people can’t move on because they need care”

Case Study 2

A discussion Group held at International Day of Disabled People (2006)

A discussion group was held at an event in Birmingham to celebrate the International Day Of Disabled People. The debate was transcribed and also recorded in bullet points. These were the comments recorded in sequential order:

“A barrier for me is not being able to walk properly, I worked in the health service as a nurse and became disabled. My disability has slowed me down and also given me depression. I can’t do the job of nursing now.”

“There was no internal support from the health service. I was told to go home and relax. I wasn’t told that I could get help. They didn’t tell me how to get money to pay bills, mortgage and look after my family. They didn’t tell me what was happening with my job, I had to find out about things myself. There was no information about what my condition was and no offer of redeployment in the health service. I had to be self reliant”

“Employers are looking to get rid of sick or disabled employees any way they can. I worked as a union rep and used to represent various disabled people at work. My experience was that employers never looked to keeping a person in work if they became disabled. It was very much “how can we sack this person under capability” or “how can we get rid of this person on early retirement?” ”

“There is a big difference between employment and work. We need to look at other ways to employ people and give them access to work. There is great value in disabled people having something meaningful to do. Direct Payments have helped us to start this process and we have set up a social enterprise. Many people have a perception that disabled people can only work in charity shops or make cups of tea. Social enterprise enables people to do more than this and to become members of the community”

“There are different types of employment”

“There was a news item about disabled people working in a firm that crushed empty cans, but they were only paid £3 per hour, which was about the minimum wage, but the disabled people concerned felt

valued and part of the community. So the company closed down even though the disabled people were happy to do the work. They felt they were doing something useful and they were happy to do it. But this was taken away from them”

“(Local authority) withdrew from the project because it was only paying £3 per hour, but disabled people were only meant to do temporary work there to help them get into employment and into the real world, so was it really all about cost cutting?”

“Disabled people don’t seem to be covered by the minimum wage”

“(DIY store) take on older people, they must get around the situation”

“If there’s a law on the minimum wage, disabled people or not, need to be paid this otherwise disabled people are being classed as lower class citizens”

“In the big world it’s about “do it yourself”

“Training opportunities are a good idea to help us to gain skills but we must get paid expenses. Disabled people are the same as anyone else. Training shouldn’t be just to start people off and then stop the process. Local authorities should think about what they are starting before they do”

“Training may be provided but on a low wage”

“Paying disabled people a low wage on a training scheme can be viewed as exploitation. I can understand that people become disappointed when a scheme closes down for these reasons but on the other side of the coin they shouldn’t be paid less than the minimum wage”

“Disabled people ought to have protection on their benefits. Many people are concerned about losing their benefits and the fear of coming off benefits can be a real barrier”.

“Many disabled people have the perception that they are going to lose their benefits totally when they get a job. Some agencies working with disabled people will even discourage disabled people from giving up their benefits for work”

“Direct Payments, whilst many disabled people have social workers or key workers, disabled people are still not getting what is their right. They are not being told about Direct Payments or the social workers don’t know”.

“MPs, councillors, unions and employers are not listening”.

“Voluntary work should be recognised – any sort of work it’s not just about getting a job. Work should be about what you can do not what you can’t do”

“We need to look around us and pass information onto other people”.

“The question is if we say that people should go out to work, then you are no longer supporting them with benefits. But we are taking people off benefit support without supporting them to get work”

“In teaching, disabled people can’t do things like cutting up stuff in the staff room. The head teacher isn’t helping, I’m a disabled person and a teacher – there’s no help, no personnel department to stand up for me. I was bullied out of my job”

“It’s not a lack of skills, it’s prejudice – I am fit and well to do the job”.

“I’m afraid not to go to work so you go to work and then get sick”

“As a black disabled woman there are no chances for me”

“I thought of taking my former employer to a tribunal but they kept losing my papers. I got too ill in the end and gave up on my case”

“You have got to look for information yourself. There is no help on benefits, it’s an unfair system – Tony Blair – it will help you with this and that but doesn’t tell you how to access help”

“The definition of work is unhelpful. I’ve done lots of work with children over the years. People ask me why I don’t get a job – but I do do work. The definition of work should be changed. I live on my todd, I do house work but I’ve spent 15 years fighting depression and working around that”

“The definition of work, the government give money to those who can’t carry out activities towards work, but things are moving, there is a historic legacy as far as jargon is concerned. There is lack of thought about the person”

“Access to information is critical and venue access – there should be more information in alternative formats and languages”

“Many companies want to tick the box “yes I have a disabled person”. Having a disabled employee is management by exception, disabled people become stigmatised”

“Physically disabled people are sat by the door – but we must get away from “if disabled people need special treatment – employers are still not providing for disabled people”

“Accessibility issues should be the norm. I have dyspraxia – I’ve had it since birth – it affects my coordination – I need small changes in the work environment – a PC and a coordinated keyboard so the employer would have to look into the IT”

“I know a guy who is visually impaired and everyone is like “Oh God! We need to make changes for him”. But this should be the norm”

“Access to information – must be able to find out information on benefits. We have staff at the (*disability agency*) who can help. Information is out there it’s just getting the word out there”

“The statutory, voluntary / public sector is traditionally better for disabled people to get jobs, but now they are talking about less jobs available in this sector. They want less stress and so more doors are shut. “The ability to deal with heavy workloads” is given as a job essential requirement and the ability to work under pressure - this slams the door on me and slams the doors of most people with disabilities.”

“Birmingham has an ambition to become a world class city of Europe. To achieve this, issues such as the barriers that disabled people face in our city need to be achieved. Accessibility for starters, before you can get a a job – the barriers in between need to be addressed so that people can at least get out and about from their own house, for example access, buildings, website, transport – all issues for Birmingham City Council to abide by before they can include disabled people not exclude them”.

“Volunteers are now being accredited for their work with (*grocery store*), working towards an NVQ for the work they do it’s in the (*agency*) newsletter this month”

“Barriers for me are my legs and my hearing and my speech and pain and last but no least depression”

“Discrimination against cancer (the fight to get DLA is very hard)”

“I need proper support from people who care and know how to move me”

“Self confidence”

“Information, information, information”

“A one stop shop for support”

“Confidence and awareness of support available”

“Exception”

“Communication, understanding, support”

“Perceptions of own and others abilities”

“Reduce jargon, especially abbreviations”

“Use of the public highway. Accessibility”

“The government’s fixation with excluding targets in mainstream schools leads to some head teachers not wanting to accept disabled people. The consequence of this is a poorer education for many disabled children which will make employment very difficult regardless of impairment”

“What if you have a disability that isn’t an everyday situation, i.e. I have sickle cell, which means I have severe pain from time to time, week to week getting work is impossible because of taking time off work”

“Communication is lacking in networking and sharing information”

“Ability to work in high “pressure environments”, “manage workloads” (often in voluntary and public sectors) are these legal? Do they discriminate? Recruitment”

“Not knowing of ways to start gaining experience for employment”

“Access to information”

“People not listening”

“Barrier – support. Support for P.N.D. seems to be geared for people getting a 16 hour job and off benefits!! What about everyone else!! People with learning disability and people wanting to do less than 16 hours”

“Barrier - transport – I am an able bodied person and it took me nearly 1 hour to get here today. Information on bus stands around the city centre did not correspond to bus numbers and routes! How are people with learning disabilities supported to get around with inaccurate information!”

Case Study 3

Leslie is in her late 40s and has been disabled all of her life. She uses an electric wheelchair and an adapted vehicle with a tail-lift to get around and therefore has to depend on having ramped access into buildings and convenient parking with ample spaces. These things alone can present huge external barriers to Leslie in her everyday life and on top of this, her own energy levels have prevented her from gaining employment :

“I think the key issue” Leslie told us “is not the type of impairment someone has but their energy levels. It is important that job agencies and employers understand energy levels—an impairment can be measured but you can’t put a pattern on a person’s energy levels. I can be full of energy for days or even weeks on end but then suddenly I can just zonk. The 9-5 model that support agencies use excludes many disabled people. There should be more online opportunities at times convenient to the service user”.

Leslie also believes that barriers are caused by attitudes:

“I think one of the biggest barriers is people’s attitudes and not believing in the disabled person’s ability to be part of the work team. I also feel that the benefit trap is a major barrier for me. If I were to come off incapacity benefit and start work, I would have to assure myself that I have a similar level of income. But you don’t know how things will turn out until you try them and you have to have some belief that there will be someone there to support you before you try something out. You need to have a great deal of confidence in other people before you make that big move”

These are a few more of Leslie’s recordings:

“Apart from the physical for example steps, stairs, over crowded office space, toilet provisions. To be taken seriously, that I am capable of doing the job. My own energy levels and not being able to do a full 37 hours or to commit to set hours e.g. 9 to 1 on a five day basis. From a wheelchair users point of view always being looked over, physically and visually (as if you are not in the room)”

“Opportunities are a big barrier for disabled people. Confidence building is very important. As I am not actively looking for work I have no recent experience of training agencies”

“I come across the day centre syndrome a lot amongst other disabled people. I joined a wheelchair user group facilitated by the health service and there are a lot of people who you know attend day centres, they have a restricted view of life. I don’t like to be lumped with the day centre syndrome”

“I think that training agencies should be more proactive in terms of contacting disabled people in my situation who aren’t visible to the system”

“I want to work when I want to, not when I have to. Flexible working is important to me. I think people should be able to work from 5pm until midnight if it suits them, it shouldn’t matter as long as you get the work done. I think flexibility is important to many disabled people and the current work culture doesn’t allow that either in terms of working hours or income”

“Attitudes need to change in organisations that employ people – there has to be change management when companies start to employ disabled people. You find that a lot of colleagues resent and resist change – even in a disability organisation who employ someone with a new disability such as a blind worker”

Case Study 4

Abdul is 40 years old and came to Birmingham from Bangladesh over 10 years ago. He is married and has 4 young children. Abdul has dyslexia and psoriasis and it is his skin condition which has prevented him from doing the work he loves best and is trained to do.

Abdul was a chef, specialising in tandoori and Bengali cuisine and worked for many years in local restaurants until his psoriasis became very bad and he was forced onto long-term sickness. Even when his condition gets better Abdul firmly believes that potential employers will now be afraid to employ him.

“I dream of a good job and good money, I am fed up of being at home. But I was even refused a job as a baggage handler because I didn’t have the necessary qualifications!”

“I have problems approaching employers – sometimes I can’t get the words I need to sell myself to employers. Job interviews are difficult, I did have one recently at a big grocery store which I found a positive experience but it was only for a temporary job. Generally I have problems at interviews”

“A barrier for me is having to receive regular medical treatment for my condition – going back and forth to the hospital – employers aren’t happy about you losing time off work for hospital treatment”

“I have lost a lot of confidence because I was out of the workplace for many years bringing up my children. I think a lot of things have moved on since I was last in the workplace, such as technology”

“I would like more opportunities to write the words to explain myself to employers. There is too much emphasis on one-to-one interviews – which I find difficult”

Abdul does not feel that he has received the right kind of support in the past from local agencies. He needs help to fill out forms and to search for jobs on the internet and in newspapers, etc. He said he would benefit from a key support worker approach. Perhaps literacy and or ICT courses. Language is a major barrier but also having confidence to sell himself at job interviews, perhaps more interview practice. Abdul believes he is able to sell himself better in a C.V. format rather than in job application forms and interviews.

Case study 5

Brian works as a support worker and coordinator of a support service for people living with and affected by HIV. A large part of Brian's work is providing advice and support to African women's groups and gay men. The type of services run by the centre include therapies, counselling, drop-in, food bank, CAB, debt crisis counselling, volunteer support, writing group, sexual advice counselling, haemophiliac group and a job club.

Brian feels that the term disability was one that was largely misunderstood and that many people with HIV, haemophilia, AIDS etc, did not necessarily identify themselves as being disabled people. He said that staff also viewed disability very much from the perspective of 'physical impairment'. For instance the centre was generally very accessible in terms of it's physical environment, although staff were not necessarily very aware of wider access issues.

This meant that there are potential perceptions which may mean that service users don't engage with disability based specialist support services because users don't identify as disabled people. For instance, he pointed out that many of his clients are African women who don't perceive themselves as having a disability in the sense that it is understood in African cultures. Similarly we discussed attitudes in some Asian cultures which might prevent disabled people from accessing support services. Similar cultural taboos exist for gay people and people with HIV, so there was general acknowledgment that this is a sensitive area.

Brian expressed a very positive approach and suggested that there was much work to be done in terms of networking, firstly within the community and voluntary sector but also linking in with statutory service providers, such as social services and the health service. He said there is much crossover in the work of different charities and health based groups. He said that often his organisation need specialist outside expertise in terms of things like benefit advice, this is where a broader understanding of the social model of disability would be useful because sometimes it is difficult for people to make the jump from being HIV positive to identifying as a disabled person for the purposes of Disability Living Allowance or similar benefits.

In terms of training support, his organisation run a Job Club and various courses aimed at equipping people with new skills. They also have internet access and are looking towards getting more funding for ICT training. Some of the biggest problems faced by their service users include language and cultural barriers, but also issues such as not having credit to make phone calls or spare income to travel on public transport. Many of the African women who use the centre have childcare responsibilities, so issues around proper maternity, nutrition and health care tend to take priority. Social isolation can also be a major barrier, so Brian's organisation try to encourage a thriving calendar of social events.

Case Study 6

Carol and Clare are development workers at a centre for deaf people. Carol is a deaf person who is undertaking research into the progression of deaf staff into management, Clare has previous experience working with people with learning difficulty at another charity.

The organisation run many services, all geared up to meeting the needs of deaf people and people who are hard of hearing. The use of sign language is very important in their services. The services on offer include an equipment service, a deaf prison service, care management, an information service, interpreting, supporting people, deaf awareness training and youth services.

Many of their service users are from black and ethnic minority communities, others have multiple impairment or other forms of disadvantage, for instance a deaf person can be a wheelchair user or a person with a learning difficulty.

For many deaf people from an ethnic minority community, English could be a second, third or even fourth language. This has an even greater impact on the person's ability to communicate and subsequently an impact on their skills level. A lot of barriers for deaf people start with the education system, which both Carol and Clare described as "generally inadequate in terms of meeting deaf children's needs" adding that "generally deaf people have therefore had a lower standard of education and have less qualifications than the hearing population".

Carol and Clare said that for many deaf people the benefits trap is a very big barrier, which may prevent them from actively seeking work. Many deaf people will feel that they are better off staying on benefits, especially when they cannot get well-paid jobs because of their low levels of experience and qualifications. The centre is therefore going to engage a specialist benefits advisor.

Carol drew my attention to a piece of research by Conrad, which found that a high proportion of deaf school leavers have a low reading age. Clare suggested that this research has been recently updated by Steven Powers at Birmingham University.

The new employment service at their centre will be funded by the Learning and Skills Council and will be part of a partnership project led by Mencap. The project will have both a further education and employment element. The focus of the funding application had to be on people with learning difficulty and what is interesting here, Clare and Carol say, is that the L.S.C's definition of 'learning difficulty' includes some deaf people on the basis of their lower educational level.

The organisation believes that employment support for deaf people needs to start with skills for life and pre-employment skills. These are skills that they probably haven't learnt at school but things they will need to develop before going out into the wider world in search of employment. The project will

include A.S.D.A.N courses as well as youth qualifications, employment coaching and creating CVs.

Clare and Carol say that there are many barriers that face deaf people in their search for employment. One of the big barriers is the attitudinal barrier amongst potential employers. As an organisation they have developed an active role in terms of marketing the potential of deaf employees to companies and encouraging deaf awareness training. Clare told me that it's a carrot and stick approach, using the DDA when it is necessary but also offering incentives to employers.

Often companies are not aware that many problems can be answered through basic technical support to deaf employees. There is also widespread ignorance about sign language interpretation. The organisation has known of cases where deaf people have been refused an interpreter even for an interview.

There is lack of knowledge about the Access to Work scheme where employers can get help to employ disabled people. Not many employers realise that the Jobcentre will fund interpretation required for a job interview. Many companies wrongly believe that it would cost them a lot of money to employ a deaf person. Clare and Carol offered the following additional case studies based on their own clients who are looking for work:

Christopher

Christopher is a deaf person who was successful in getting a new job and then applied to Access to Work for an assessment to get assistance. But Christopher had to wait many weeks for an assessment and then encountered a series of long delays. Eventually some help was offered by Access to Work but not everything that Christopher felt they needed. Eventually Christopher gave up and left the job.

Clare and Carol felt a lot depends on the assessment officer and this differs from one area or office to another.

Focus group held at a Birmingham based centre for Deaf People

A focus group was held at the centre in Birmingham which provides services to deaf people and people with hearing impairment. 5 service users came to the focus group, 4 workers from the centre – some of whom were deaf people themselves and three BSL interpreters. The service users were deaf people who have recent past experience of looking for work.

The discussion, mainly conveyed through the BSL interpreters, was recorded to audiotape. Below are some key quotations from the focus group:

“I was working with my father and brother but was made redundant 14 months ago. Whilst my brother and father who are both hearing have found new employment, I have not and I think my lack of success in getting employment

is due to the fact that I am deaf. It is very stressful not getting a job. So I went to college, but I failed to actually get into some courses. I've tried and I've sent letters out to people, but I've never had responses and it just gives me stress that I haven't had work for such a long time. My failure at college is also related to my deafness because people do not give me information when I fail to pass a test or interview, etc"

"I feel that job centres are reluctant to assist me to do the training that I want to do. If I wanted to go and learn an HND, will there be funding from the job centre for me to do that? They won't support you with HND funding. Well, I just thought well the job centre is nation wide, but they won't offer that support. I don't know why they won't do that. It looks like they're not bothered with deaf people. They don't think about the communication barriers. They think it's a problem by bringing in an interpreter and having to give us extra help. My opinion is that I've seen that and they're not bothered"

"Sometimes I go to the centre to look for jobs with a support worker, but the problem is, a lot of the time interviews are over the phone which aren't appropriate for somebody who's deaf. So they say, oh send in your CV and then we will get back to you and my advisor has done that, but they've never had any phone calls back"

"Yeah I sent out a CV lots of times, but I've never actually had a response. I just want to know what's happened, what's the information on how I can move forward and it looks like maybe they received the CV and seen that it's a deaf person then they just throw it to one side and I don't really know why they do that"

"I went in, had an interview with an interpreter and we had a discussion and they checked me on the computer and I'm quite a fast typist and they said "oh, the problem is, if there's a fire there's a risk for you being deaf". Well I said "that doesn't matter, if there's a fire I can see everybody leaving. I've got my own eyes, I can see that" and they said "oh no it's a fire risk for somebody who's deaf", they know I can't hear the alarm, so they said "sorry you can't get the job" and I couldn't believe it just over something as simple as that. I was so upset. I mean, if there was a fire, if there was a person in a wheelchair it's the same if there are obstructions in their way"

"Well the problem I think is lots of employers need deaf awareness, so they know deaf people are the same as hearing, or are as equal as people with hearing. The only thing is we can't hear. People I think, need to have deaf awareness training, so they can become aware of that"

"I've been many times posting off applications, filling out loads of forms, sending my CV everywhere and I'd get a rejection back and it's very disappointing and they said, "well how are you going to communicate?" and I said, "I can lip read" but there's never any access for signing there. Same as before when I worked in Redditch, everybody was hearing and I was the only deaf person there. I could communicate with hearing people and the boss didn't sign or anything and I had to communicate and I told them about this

and they said, it was possible, but I can write things down as well. Obviously, I don't use the phone, but I can write down and speak to each other and, obviously if there's a sort of speech coming over the tannoy system, that's difficult, or if there's an emergency and you have to get out and in meetings, obviously, everybody is hearing and information's all in hearing, so I've had supervisory responsibilities and I've helped people at work and sorted things out, but there's never been any signing for me during my work life career and I worked there for fourteen years"

"Yes, I have the same issue. I went to (*employment office*), I gave in my card. They have a look on the computer to find me, as they do, with the details and they come over and they shout the name out and obviously, if I'm looking down, looking at the adverts, or whatever, I can't hear them talking. I don't respond when they call my name and maybe someone will come over and tap me, but it's a waste of time. I'm sitting there for ages, they know me and they should know I'm deaf and, perhaps we could get it over much quicker if things were a bit more efficient, if they could help me and phone for me and try and help me to get a job. The (*agency*) don't help me at all; I think they're a waste of time. They haven't helped me at all, it's very, very stressful".

"Are we all in agreement that deaf and hearing people fail jobs and you feel that we're below hearing people who find the jobs, you all definitely agree with that, and everybody has said yes they do"

"I've been to the (*job agency*) and they actually have useful interpreters there and they give support. There's a lady there who supports communication and discussion, they offer support with creating a CV and trying to find the interviewee a job and they give you lots of choices of different jobs to do and they can make phone calls. They're supportive and they've said they'll get interpreters".

"Since I came to the centre, I've been out talking to several of the DEA's and job centres and there does seem to be a vast difference between different job centres. Some are a lot more supportive. The thing I'm being told most though by DEA's, is that they don't have many deaf clients. Now my argument is, yes they do, but deaf people are not going there because they are not finding the right help there"

"I was going to ask, can we take it then that the general experience is that job centre plus don't have any interpreters, no staff that use BSL, the service isn't even offered to people and yet there's an organisation you mentioned, Work Directions who are the opposite, seem a good example"

"That's correct, yes, they supply interpreters regularly, but that's because it's in Birmingham town centre. A lot of deaf people live quite a long way from Birmingham town centre and it's great that they have interpreters, but you have to travel. What about local services, that's what I'd like to know?"

"Can I ask people, if you had a magic wand, or you had the power, if you were the minister for employment, what in an ideal world, what changes would you

make. I mean, number one, to the job centre plus system and then maybe, what changes would you make to employers. What would you make sure employers do, but firstly at the point of looking for a job, if you had the power to change things, what changes would you introduce into job seeker plus that would help deaf people?

“I think awareness is the key. Awareness of interpreters. How to use interpreters. If a deaf person comes in, awareness that you need to book an interpreter without worrying about the funding. I think they need a good full awareness of what an interpreter is and what that entails”

“Application forms are all different from different companies. You have to follow their corporate application process, there’s not one standard generic application process for every company and sometimes you have to go to the job centre, sometimes you have to have an application form from the job centre, sometimes it’s a corporate application form. So, what about if you need an appointment very quickly, an emergency appointment, there’s a difficulty there as well. That would need to be changed, I think that’s something that needs to be talked about, because sometimes you ask the interpreter to help you with translating the forms and that. I’ve done that before, but that can delay things. It would be nice if there was somebody straightaway there, without having to book and have that delay in the process, wouldn’t it?”

Case Study 7

Debbie is a 35-year-old woman who has learning disabilities. Every week Debbie attends a local job club run by a charity. She goes there early because of the buses. She lives in a residential home and finds the experience of travelling to the job club a useful thing to do as it increases her sense of independence. In her recordings she highlights the personal and social value gained from attending a job club without pressure from other people. During the action research period I worked with Debbie using an approach of writing directly to supermarkets and other employers. Debbie is particularly interested in supported permitted work up to 16 hours a week in order to preserve her benefits. During the research I became very aware about how difficult it is for some people with learning disabilities to explain their situation and what they ideally need to complete strangers, particularly employers. Debbie is an example of someone who is easily missed by the system and assumptions easily made that she is content to do the same things for months or years.

“I want to find shop work. I did voluntary work at a charity shop for a couple of weeks before Christmas but I had to stop coming there because I was leaving too early because of the buses. They didn’t keep me because I wasn’t quite capable of doing the job. I don’t know any skills and no I haven’t done any training so don’t know any skills”

“I worked at (High Street health and beauty shop) for 10 years but they ran out of stock. I used to clean the shelves, tidy up and I talked to the customers.

It was in a busy city centre shop. A couple of times a week. I don't know what to do with my time now – I sit in my bedroom a lot listening to music”

“I travel on my own and have a bus pass. I attend the job club once a week on a Monday. It's my own decision to go to the job club. I use the computer to look for jobs but I need help to look at the computer. I have applied for some jobs but don't get anywhere”

“When I first started working at (*High Street shop*), I can't remember who helped me get that job. I was made redundant following the shop closing. I get benefits; the staff at (*residential home*) give me my money. I miss getting a wage like when I was at work”

“I have printed off a record today from job search. I'm looking for jobs on the Jobcentreplus website. It is very difficult to spot jobs where support is given to people with learning disability”

Case Study 8

Marlon is 22 years old and has a learning related disability. At the time of the research he was training to be a chef at a working restaurant funded by Birmingham City Council. Marlon believes that a major barrier for people with learning disabilities is the attitude of other people, especially employers.

During the action research phase Marlon set out to try to raise awareness about people who live with the label of learning difficulty and to dispel some of the myths and stereotypes which too often become barriers that stop people from progressing in life.

With the support of the research facilitator, Marlon wrote a journalistic article about the attitudinal barriers experienced by people with learning disabilities which was published on a current affairs website run by a well know journalist and broadcaster. Marlon has subsequently been invited to be interviewed about these issues on a local community radio station.

Marlon has found the experience of being able to express his views very empowering. He does not see why people with learning disabilities should not have big ambitions given the right support:

“As soon as I finish my catering course I would like to go travelling to see more of the world and use my food skills as I travel, learning about other cultures and the way they cook. Since I've been working at (*restaurant*) I've been finding out more about people with learning difficulties. Maybe one day I could open a restaurant they could come to and get a good wage instead of being on benefits”. Here is the transcript of Marlon's article:

Raising Awareness About Learning Difficulty

Marlon is 22 years old and comes Birmingham. Marlon has learning difficulties and is training to be a chef at the (*training restaurant*), a restaurant based at (*local authority funded centre*). In this article Marlon wants to raise awareness about people who live with the label of learning difficulty and dispel some of the myths and stereotypes which too often become barriers that stop people from progressing in life.

Marlon was first given the label of learning difficulty when he was at primary school. Teachers noticed that Marlon was slower than most of his friends with things like writing, reading and maths. He was therefore transferred to a special school. Marlon looks back on this experience with some sense of sadness about losing his friends:

“The teachers said to my parents “Marlon can do things but he has a learning difficulty”. But what I don’t understand and can’t find out is why I couldn’t stay in mainstream school with just a bit more time for copying from a black board or more time doing maths, English, science, etc.

My mom told me I may have to move school. From primary school I moved to a special school and then to special secondary school. Moving school I felt upset about leaving my friends who understood me. I am happy that I have kept many of my friends from primary school”.

Even though Marlon acquired the label of having a learning difficulty and moved into a segregated education system at an early age, he has maintained friendships with many non-disabled childhood friends, some of whom have gone onto to university:

“Half of my friends are in university or doing high jobs that I couldn’t do. I never get jealous, I just ask questions about what it is like and always show an interest in their lives. My friends at university love that about me because I ask questions and I don’t let anyone knock me. I have known one close friend who is now at (*university*) for 17 years, some one else is training to be a professional tennis player and another friend is training in photography”.

Something that Marlon is keen to express is the great amount of difference that exists amongst people with learning difficulty. His recent experience in the training kitchen and restaurant at (*training restaurant*) backs up his view that the term learning difficulty is a huge umbrella that covers many different people from different backgrounds and with different abilities and skills. Marlon believes that other people are too quick to make assumptions about anyone with this label.

“First of all it’s a shame that people could have the same rights as other people but they are being judged because they have a learning disability and secondly I feel everyone with learning difficulty is put under the same umbrella. I mean, if you are working with someone

who has the same disability as me, they are not necessarily exactly the same. We can each be better in our own way.

There are good qualities in everyone but employers don't see this and just want to give you a job and let you just do that job until you get bored, when they should be encouraging you to learn new skills.

I think employers are noticing someone with a learning disability and thinking that they know nothing, they are not aware and they should be aware. I would like to write an article to tell people more about learning disability – aimed at employers and businesses to try and educate them”

Marlon believes that people with learning difficulty shouldn't be treated differently unless it's necessary. In other words, rather than refusing to employ someone, employers should try to come up with a solution so the person can do the job. He feels that he is achieving a lot personally but could do a lot more with support and encouragement. For instance he worked for four and a half years at a well-known fast food chain and was promoted to the position of dining area host within 6 months but after that was never considered for further promotion such as manager training.

“I got promotion to dining area host, which basically means customer care, customer service and cleaning. But I wanted to go higher in the company but felt that they weren't willing to delegate a manager or supervisor to have 1 to 1 sessions with me to go through it so I could get promoted higher. It was a case of “if you don't like it then get another job”.

As soon as I finish my catering course I would like to go travelling to see more of the world and use my food skills as I travel, learning about other cultures and the way they cook, then maybe come back and say to my family I've found a place to try out. If I try and fail at least I've had a go”.

“Since I've been working at (*training restaurant*) I've been finding out more about people with learning difficulties. Maybe one day I could open a restaurant they could come to and get a good wage instead of being on benefits”.

Marlon has recently been sharing his knowledge and skills with young people at (*name of special school*). He feels that cooking and catering are good careers for disabled young people. Marlon also believes there's more to catering than just working in the kitchen and restaurant areas, he is keen to do some marketing as well. Part of his job entails going around the offices on the site with a trolley and while doing this he promotes the restaurant to staff he meets:

“ At this place because of the trolley I can work in the offices, meeting customers: what's your name? What do you like? Trying to get

customers to recognise there is a restaurant here and you are welcome to have your food and sit in the restaurant. That's what I like about catering – I like the customer care, cleaning, basically making sure everything is suited for everyone”.

So the next time you meet someone with a learning difficulty, don't be too quick to put them under one umbrella, as Marlon says, everyone is completely different:

“Basically, people probably moan saying you shouldn't put them in different categories, but people do need to realise we are all different, even people without a learning disability – we're all different”.

Case Study 9

Nick is 44 years old. Coming from a family and local community which instilled in him from a young age a strong work ethic, he trained as a mechanical engineer which later led him to running his own successful motorcycle shop. But Nick's hard-grafting entrepreneurial life-style came to a sharp finish 9 years ago when he developed a collective syndrome of illnesses which left him permanently ill, drained of energy and dependent on high doses of strong pain-killing medication.

Over the past 9 years, Nick's world has changed dramatically:

“You lose your friends and your social life when you become long-term disabled. You don't have money to go into pubs with your old mates and you start socialising with other disabled people. Inactivity is not something I was used to; I worked since I was an apprentice after leaving school. Everything impacts on your situation once you have a long-term illness — finances suffer, you can't pay bills or get things sorted out, your diet suffers because you can only afford the cheapest foods, you're dependant on strong medication, you get depressed, your relationships suffer—these are all the various dynamics of 'the rut' ”

Because he knows he can no longer do a physically demanding job, Nick has instead tried to develop other skills and employment related interests:

“I can't ride motorcycles anymore and I get chronic fatigue. I just don't have the focus or energy to work on bikes so I've developed a new interest in research. I also have plans to launch my own online business but there just isn't the support to help me do it. I have a lap top computer but I cannot afford to get access to the internet. I believe that some of the money that the government throws at employment and training agencies could be better used to give people in my situation real practical support to empower ourselves, like giving people free internet access so we can get in touch with the rest of the world and sell our own business ideas”

Researcher's Recordings from a Home Visit and Interview with Nick:

Visited Nick at his home on 25th June. Have had various telephone conversations with Nick recently in which he related to me that he has been going through some challenging times on a personal level because he is attempting to come off very strong pain killing medication that he has been on for some 10 or more years.

Nick goes to great lengths to emphasise the powerful impact of the medication on his life and the subsequent impact of trying to come off the medication after so many years, whilst also trying to re-evaluate his own life, get an accurate diagnosis and prognosis from his medical advisors and give support to friends who are in similar or more challenging situations even than his own.

When I met Nick at his flat he was in obvious pain and discomfort at times but also very articulate and keen to read to me his extensive action research recordings. Of all the people who have participated in this project, Nick has perhaps been one of the people who grasp the concept of action research most fully and is able to convey a very holistic approach as a co-researcher.

Listening and talking to Nick I am constantly reminded of the purpose of this research and the broad, intertwined mesh of issues and barriers that impact on the lives of disabled people. Also about how these barriers impact on the day-to-day psychology and mental health of disabled people. Sometimes as a researcher it is easy to understate the various separate issues and thus intellectually trivialise their impact. However, I find that Nick is extremely articulate in providing a powerful testimony of how one barrier can impact on or create another, the cumulative affect being that the individual literally feels they are drowning on every level of existence, whether this be emotional, practical, health, diet and exercise related, or concerned with mental and occupational stimulation, relationships, finance, housing, etc, etc.

Talking and listening to Nick I am increasingly convinced that any approach or practice that merely focuses on one aspect of someone's life through a narrow focussed motivational psychology approach runs the risk of being superficial.

A sample of Nick's recordings:

"You've got to help yourself before everything gets too much"

"People are trying to survive on 2 or 3 days money a week, so they don't get enough of the right food and then on top of that is intense boredom - but people can't help themselves"

"There is a lot of apathy around because people feel so disempowered".

"The long term objective is to start inward reflecting within me. I want to use a flow and cycle methodology of keeping a self-reflecting record. Not just writing actions down but enabling me to do mental tracking. If you have got fibro myalgia then you need to ask questions".

“My aim is to launch my own internet based business. I have also recently become involved in the Two Wheel Strategy for the West Midlands which is about encouraging the use of motorcycles to help ease congestion”

“Putting simple things back into everyday life. Other disabled people and ill people experience a similar cycle of barriers (dynamic of the rut). When you take strong medication or you become ill, other things start to go out of the window. Because of lack of money you have a bad diet and a poor general level of education about your diet. You survive on biscuits and beans. Your bills start to get out of hand. You become bored so some people start taking heavier drugs or start watching television all of the time which has a strong cathartic effect on the viewer. Some nights you sit and watch television for several hours but can't recall what you have actually watched”

“Then there is a breakdown of your relationships and you start to get feelings of anger because you put your head out over the precipice and it's not a good state out there. You feel depression because you are constantly dealing with negatives, against which you feel useless – you feel you can't do anything about it. All of this is reflective”

“Medications have a half life. Being on strong medication is a sleep that you can't wake up from. It is a barrier; you can't go into an industrial environment on medication. I feel aggrieved”

“I loose track of household chores, washing and ironing, paying bills and dealing with red tape. The red tape increases because you are not managing it. You are not even surviving, I have to buy 10 pence bread”

“Self employment requires a level of fitness that is needed to start your own business. You need both mental and physical strength.

“The longer you are out of work, the worse your problems grow. I know people who go to bins at the back of supermarkets for their food. But even the supermarkets are now emptying everything into skips and locking them away at night”

“I have found that having standing orders helps me to pay the bills from my bank account. By strict financial management I have managed to save my own property. But not all people with a mortgage can cope and it is common for people to get into debt”

“Nowadays I would expect at least the basic minimum wage if I were to start working but that would be difficult to sustain me”

Case Study 10

Erica is 55 years old and has worked all of her life as a teacher. Erica loves teaching but in recent years she began to develop a very strong allergic reactive condition, which made teaching or employment par se, extremely

difficult. Tests revealed that Erica is allergic to the chemicals, which are used to clean white boards.

White boards are increasingly used in the school classroom, replacing blackboards and chalk. Erica said that her experience was that little attention was given to this issue and reasonable adjustments were not provided in the school she worked in and she therefore felt coerced into early retirement.

At the age of 55 Erica feels she is too old to start a new career that would bring in the income she had been on for so long. She is trying to get supply teaching in schools where whiteboards are not being used, but they are becoming few and far between.

Erica is a writer and published poet and author. She is a member of a writer's group in Birmingham which is run on a peer-to-peer basis, members giving advice, support and being critical friends to one another. She said that a number of disabled writers have become members of the group but it is not exclusively aimed at disabled people. Erica is campaigning for an end to the over-reliance on white boards in schools (for instance she said that smart boards are an alternative) and for more research to be carried out.

She highlights the potential for more home working opportunities for people with similar conditions to herself and she would like to see greater use of technology to provide these opportunities.

Case Study 11

James was made redundant after working for over twenty years for a large manufacturing company in Birmingham. James has been disabled for many years - he has diabetes compounded by other physical impairments. Throughout the years of his employment James felt that he was on the whole well accommodated by his employer, managers and colleagues. However, problems arose when the company expected him to work full time when he could only manage part time work due to his condition. He therefore took the option of a redundancy payment combined with early retirement due to ill health grounds.

James feels that there are a number of barriers facing him now that he did not face when he was a younger person starting out in a manufacturing industry.

James feels that his age is increasingly against him in the job market; he believes that he is a victim of the declining manufacturing industry in the region and would therefore have to retrain in a totally different area; his income has dropped considerably and whilst he received redundancy pay, he has long term concerns about how he will ever get back to the level of income he was used to.

James also says that his diabetes and other medical conditions have got worse over the years but because it was a gradual process, his previous employer made reasonable adjustments and other accommodations over a

period of time. James does not believe that a new employer would be willing to make the same level of adjustment on initial employment.

James completed a phase one research questionnaire shortly after becoming redundant and agreed to have a more in-depth interview during the action research phase six months later.

Since being made redundant, James has tried to budget the income received from his redundancy payment but has mounting concerns about the future. He has used the period of short-term financial security provided by his redundancy payment to review his own skills, his medical condition and his employment plans. One of the most valuable things that James has done is voluntary work:

“I think voluntary work is a brilliant way of getting work experience. I have also been going back to college and gaining new qualifications. Doing voluntary work at a disability centre has also helped me to gain new knowledge by doing some of the in-house training courses – this has been really helpful”

“I am still living on my redundancy, but need to resolve something soon because I don’t know what will happen when I run out of money”

“I didn’t expect to do all these new courses when I left work, I also enjoy the voluntary work because it allows me learn from other colleagues. Because of the redundancy package, I was able to go back to college and will therefore feel more confident in the workplace”.

As the focus of James’ action research he has explored ways of diversifying his experience. Something he is very interested in, but has lacked past opportunities to engage in, is creative writing about sport, heritage and history. In a voluntary capacity he has become involved with a community-based magazine and in the past six months has had two articles published by the magazine both in print and online:

“I get on well with people. One of the workers here has got me into writing articles and doing promotional and marketing work for a magazine. It’s helped me to diversify. I enjoy writing but obviously you don’t get to develop that as a skill working in the car industry. It’s not just about the creative writing, but it’s developing the skills of research, writing and proof reading your own grammar and spelling”.

“It’s good to have encouragement to do new things and the flexibility and time. I would have flexibility on incapacity benefit but not on JSA or New Deal. They want me to return to work – even though doing voluntary work is helping me – they feel you should be looking for work”

“I need to find out how to get more money once my redundancy runs out. How do I service still doing voluntary work, as it has been so important? Through the voluntary work I have been doing training to help me to go into the field I want to work in – advice and guidance. I am doing NVQ level 3 but only

because I am able to do a voluntary work placement in this field. My worry is that going onto benefits I won't be able to continue the NVQ"

"Today I am ok but I have severe asthma, back and arthritis problems. I find that being a diabetic, diabetes as a condition is misjudged by the public, people panic when I have an asthma attack or go into a diabetic reaction. People who have it know how to control it in certain ways – they can sort it when left to their own devices. If I was in trouble I would ask for help – sometimes you just need to sort things out"

"I am in a comfort zone at my voluntary work placement because people understand my disability. People at (*car company*) were not always so understanding – if I took time off I was put back on jobs that affected my breathing, so was often in dispute with my managers. It's something I now have to take into account in my search for work, is an employer going to be sensitive and aware about my condition – the managers and your colleagues?"

Case Study 12

Sandra is a 42-year blind woman. She has not had paid employment since 1981 but has not been inactive during this period and has done voluntary work for a number of organisations, especially those organisations that provide services to other blind people.

Sandra has developed a number of skills during her voluntary work, such as typing from audio to text, something she feels would be a marketable service for any business or company that needs to record meetings and then have them typed up.

But Sandra feels it is very difficult to get on the first rung of the self-employment ladder:

"If only I could get help to get started, it would be a great home-working idea".

I met Sandra in her home on 3 occasions. Following earlier discussions arising from Sandra's questionnaire, we identified that an area that Sandra wished to explore was around home working, doing transcription from audio format into text. I therefore gave Sandra two taped interviews to transcribe as an exercise for her to develop and evaluate her own skills in this area and to explore this as a potential way of earning money through home working.

Sandra feels that this is work she can do well as a blind person and has experience in the past of transcribing audiotapes to text in a voluntary capacity for an elderly man who has since died.

Sandra expressed some initial difficulties with the process of transcribing the two tapes because both of them were recordings of groups of people meeting. The first one was an oral history tape and the other one was a meeting of

several deaf people who were communicating through British Sign Language whilst their interpreter's voice was recorded.

We discussed whether Sandra found it a useful experience and whether she could realistically try and develop home working opportunities out of audio to text transcription. Sandra talked about the difficulties she had initially had and also difficulties around understanding accents, for instance the older man she used to transcribe stories for had a broad Black Country accent which was sometimes difficult to follow.

Sandra thought that it would be difficult to make a full time job out of this work and said she would consider something like supported permitted earnings working part time at home. We talked about what sort of agencies might give her this sort of work such as oral history groups or agencies that organise public meetings and need minutes and discussions transcribed to text. We also talked about permitted work and agreed that in order to do this sort of work and in order to fulfil the regulations of permitted work she would have to be guaranteed a regular wage at a fixed amount for a medium to long-term period of months.

We agreed that as well as being an issue raised within the action research phase, it would be important for Sandra to continue to explore this as a future option.

Case Study 13

Jake is 23 years old and has been a disabled person all of his life. Since leaving school at the age of 16, Jake has done a number of courses and attended two colleges, which cater exclusively for disabled students, but he has never had paid employment. Jake feels that he is trapped by the general disadvantages of being a disabled young person in the job market combined with the restrictions imposed by the welfare benefits system.

Without work experience he cannot prove to employers that he can do the job on offer or convince them that it is worth putting in place some basic reasonable adjustments in order to give him a chance. But it is also impossible, or at the least complicated for him to gain work experience whilst receiving disability related benefits.

For example, once a year Jake is invited to teach on a course for social workers at a local university. He enjoys this work and feels that he is making a valuable contribution to the education of new social workers, especially around disability issues. But Jake is unable to claim a professional fee for this work and has to settle with his travel expenses. He told us:

“The impact on benefits is that there is a risk in receiving money when on benefits. I can't afford to take that risk. I am considering going on Incapacity Benefit because when I worked out how much things cost to live—I think we worked it out that I'm just breaking even in terms of living costs and stuff.

Sometimes it's better to make the system work to your advantage. It's quite sad though but that's the way things have to be"

Here is a sample of Jake's recordings:

"Because I was talking about the same thing last week, some people can't seem to get to grips with the system because this person said to me "you can work for so many hours before they stop your benefits"

"...Fine, but that should not be the case, why should you be made to work so many hours before... the system sounds daft to me... because people say to me "talk to Jobcentre Plus", yes but I'm sorry, why should I bother because they try to convince me to work which I physically can't because as I said some time ago to you, I am better off not working, I'm actually better off having absolutely nothing in my bank, I know it sounds completely daft. Because in my new place I get certain things paid, why? Because I don't have much money, for example, I've had people working on my place for quite some time for free, don't forget, only because I don't have much money"

"Because if I start claiming something like £150 for teaching that could seriously change things. So that's where it's the system that's completely wrong"

"So the whole system's a shambles but I can't think how to change it. Once a year I do teaching sessions for 2 days at the college. They determine that I just get £20 travel costs and I go to focus group meetings every month and get £20."

"The impact on benefits is that there is a risk in receiving money when on benefits. I can't afford to take that risk"

"It seems like a one size fits all sort of system, that's where the problem lies because the whole lot needs a complete overhaul because I'm doing some auditing of youth centres across South Birmingham – fascinating – you summed up the point yesterday – it's young people's attitudes because I went to this youth club and they were 10, 11, 13 and I tell you their attitude was fantastic but I found the boys weren't so keen – they sat back and didn't say much"

"This is why I feel it's so important when I audited this youth club because it became quite funny in the end because the girls were actually arguing amongst themselves over who wants to take me up in the lift. After about five minutes arguing about it I was thinking I think I've cracked it here just to get them thinking about it, that was my key thing"

"I believe that I could have a role as a disabled person going into youth clubs to do awareness raising not just ad hoc. Should start with ages 4, 5, 6 to begin with because then I'm sitting there and they can't get a numbed brain because it's fact sitting there, part of life, not in a sort of made-up thing, it's a fact of life"

Case Study 14

Patrick is 36 years old and has a mild learning disability and dyslexia. Patrick believes that his dyslexia stops him from accessing training and employment:

“I went to a special school. We did lots of normal lessons such as woodwork and English but not many exams so I didn’t get qualifications. I was never any good at maths but enjoyed most subjects”

“I didn’t get much support at school for my dyslexia. They did say I was slow at reading and writing but no one diagnosed it as dyslexia or if they did they never talked to me about it. I was given the label of learning disability, I think this is correct but my biggest problem is reading and writing”

“This has always been a problem all of my adult life. I would find it impossible to fill in application forms or write letters without support, so this is a big barrier when trying to find employment, training or courses. I find it very difficult to use the internet, I have a computer but the only software I can use is Word Pad. This makes it very difficult for me trying to get into college to do courses, because I would need support to read and write at college”

“I attend the Jobcentre and there is a DEA who does recognise that I have dyslexia and she appreciates the barriers I am up against because of dyslexia. She put me on the ‘Right To Read’ course about 2 years ago, I did this for 2 hours a week every week and it helped me a lot. Not all staff in Jobcentres have awareness of dyslexia, but I generally go to (*named DEA*) who helps and supports me”

“I also attend the job club at (*named centre*) every week. The staff help me to read and fill out application forms and to search online for jobs. I haven’t found this one-to-one level of support with reading and writing anywhere else. I have difficulty logging on to computers or to search for websites. So at some employment services you end up feeling stupid because the computers are there but I don’t know how to use them. It is hard when you can’t even read the job information”

“I have done work experience but I didn’t need to read or write for the placements that I did in the past so there wasn’t a problem. I was giving social and mobility support to residents in an old people’s home and once in a hospice so it was more practical and verbal support required”

“At the last work experience placement I did at the residential home the managers said “you need to go to college if you want to make a career in the care field”. A lot of people have advised me to go to college but for some reason the Jobcentre have discouraged me from going to college, perhaps because the hours may clash with being on benefits, I don’t really know. But it does make it difficult to get a career in care work without these certificates”

“I am applying to (*named colleges*) at the moment. I want to do an introductory course in health and social care. I have had help from (*agency*) to

fill out the application form for (*local college*). It says in the application form that the college will provide support to people with dyslexia so it will be interesting to see if this happens, even for the interview I would need someone to support me. I have also applied for an escort job with (*local authority*) which involves helping disabled children on transport to and from school”

“My research question is about how much support is really available to people with dyslexia, especially from public bodies such as Birmingham City Council or from colleges and Jobcentres”

“I know what I want to do in life but it takes time, I don’t want a dead end job, but I do know what I want is to have a career in care work for which I need certificates, but without reading and writing support this becomes very difficult”

Case Study 15

Two meetings held with Graham, one at BDRC and one at his home. Graham is a young disabled person who is well educated and went to (*college for disabled students*) where he achieved A levels and GCSEs. Graham has a strong interest in journalism, radio and creative writing.

Graham lives with his parents but has personal assistants. He has a good relationship with his parents who give him lots of support in terms of his independent living, but also lots of personal space to live his own life.

Graham is very active in the voluntary sector and is a DJ on a hospital based radio station. He co-presents a radio programme every week, the show features music and stories. His participation is purely on a voluntary basis.

Graham would like to make a career in media or journalism. As an offshoot of his experience in hospital radio he records his own programmes through a station he has created himself. He records the shows onto audio CD, broadcasts them live on the internet every few weeks and also produces them on CD. He also raises sponsorship to help him to meet production and distribution costs.

Graham is very keen to develop his skills and experience in this field. Through this voluntary work he is gaining valuable expertise not just in media production, but also in the skills needed to be an entrepreneur.

Graham faces many barriers in his everyday life both in terms of mobility and transport, physical access, independent living and a degree of communication impairment. However, once these barriers are overcome, Graham possesses a huge sense of drive and personal ambition. For these reasons it is not surprising to learn from Graham that he is pursuing a path to economic engagement through entrepreneurship / self or freelance employment as opposed to relying on employers to recruit him and then make reasonable adjustments to accommodate him.

As part of his own self-development, in terms of diversifying from the audio medium, Graham expressed an interest in writing some journalistic articles for a community magazine, but to choose a subject of enquiry which would involve him going into the community in his electric wheelchair and interviewing local people. We therefore agreed that he would write an investigative article researching the accessibility of local shops, comparing a family run shop with a big national supermarket chain. Graham interviewed the two managers of the shops and his article was published in the summer edition of the magazine. Graham has subsequently authored another article which is likely to be published in the autumn.

Graham's long-term aim is to get more work experience in journalism as a volunteer and later to try to get into paid freelance work. But as a disabled person he obviously faces many barriers and has to overcome the benefits trap, in other words to earn enough money to survive independently.

Case Study 16

Alison is 37 years old. She is a wheelchair user and also has visual impairment. She does not have her own transport and relies on taxis, which can be expensive. Alison lives in a sheltered housing scheme but feels very isolated and cut-off from outside leisure and social activities. Alison does occasional voluntary work, which includes mentoring disabled school children but feels that her lack of contact with mainstream society over several years has left her feeling low on self confidence and generally sceptical of schemes and projects that offer support.

The walls of Alison's flat are papered with certificates she has gained from courses and training schemes she has completed over the past few years, but none of them have led to permanent employment. Her ambition is to be a journalist but before she can even think about employment or training she has more basic issues to sort out:

"I'm desperate to move and I am trying to get direct payments to employ my own personal assistants. Until I gain control of my own life and become more independent, it is pointless even thinking about work. I would then need help to find and identify specific jobs that I would like to go into. I haven't been successful at that in the past"

Here is a sample of Alison's recordings:

"I am writing about what I feel needs to be done in the housing complex where I live. I feel that I can not improve my life until my housing is improved. We need a maintenance person to do odd jobs around our homes on request. There is no choice about what telephone lines are installed here. At weekends there is no one here on call for me or my neighbours.

"On 4th June an officer from the (*housing agency*) visited me at home. I also had a visit from someone to discuss direct payments. This will help me to

move nearer to being able to work. Things are looking up but slowly. I had a meeting with a key worker to discuss my welfare.

“On 14th June a worker contacted me from (*support agency*). He is an old colleague from (*agency*) and he has been reassigned which is good because he is contacting me in the next 2 weeks. This can't happen quick enough for me. Things are very slow in my life, but when things start to happen the way I want them to happen, it all happens at once. Prayers have been answered. My tears before I go to sleep get answered in some way”

“Today is the 14th June and (*named key worker – independent living support*) called me back to say a social worker from physical disabilities team is coming out to see me over my direct payments. I'm really hoping she will see that I need direct payments, as this is crucial to change my life. I'm glad of the help of my key worker to chase up appointments and help to fill out forms”

Case Study 17

Lifelong teacher Guy is a self confessed workaholic. Head of Science at a well-known Birmingham school, Guy worked 15 hours a day, sometimes 6 or 7 days a week for 25 years in a vocation he loved but had to retire two years ago due to a deterioration in his rheumatoid arthritis. Guy told us:

“I had to take ill health retirement due to an inability to maintain safety with handling materials. As a science teacher, the deterioration in my manipulative skills meant I could no longer preserve a safe environment for my pupils which may have resulted in an injury to a child if I had continued work”.

Whilst Guy feels he is fortunate in terms of his subsequent income, being made up of a combination of permanent health insurance, teachers' pension and Disability Living Allowance, he is less happy about being inactive when he feels he still has much to offer both to the teaching profession and to society in general from his immense store of professional knowledge, experience and commitment. Guy has mounting anxieties about the future:

“When I am 60 I will lose the insurance and will begin to feel the financial pressure I am sure. It is then that I would not mind supplementing my income by providing private tuition in sciences and mathematics. My state pension would not be realised for a further 5 years. The outcome of so doing, according to the teachers' Pension Authority would be to initiate a review of my circumstances and probably stop the pension. The inflexibility of the rules of 'ill-health retired teachers', when there is a grave shortage of science and mathematics teachers seems incredulous”.

Here is a sample of Guy's recordings:

“As Chairman of the (*local support group*) I come across many patients who have, owing to their condition, been forced into early retirement and a greatly reduced financial income. Some, like myself, find solace in voluntary work, which keeps me busy and mentally active. I have been a workaholic for 35

years whilst teaching as Head of Science and, simultaneously, also as a Housemaster of a boarding house of 115 boys. When one has worked 15-hour days for 6/7 days of the week within a vocation that one loved, it is difficult to suddenly find oneself inactive. It is no wonder that many teachers die of heart failure within 8 years of retirement”

“I feel that the 50% pension supplied by the government is ok, but I also feel that they need to be more flexible in the area of private tuition or perhaps supply teaching to allow ill-health retired teachers to supplement their income legally”

“Intolerant legislation prevents me from exercising the teaching skills that I have acquired over the past 35 years. I was given an ‘excellent’ in a recent OFSTED inspection with a ‘faultless department’ recognition. What a waste it is that I cannot exercise these skills”

“I could still teach science but the handling of dangerous substances would be prohibitive in this subject. The use of a technician would have helped but was a very expensive option. Access To Work had already helped a great deal in the provision of teaching aides (interactive whiteboard, etc)”

Case Study 18

Terry is 56 years old, he has been visual impaired since childhood and his remaining sight is slowly deteriorating. Terry is very skilled in the production of audio media, he produces a local talking newspaper for blind people and also does a lot of voluntary work around things like oral history and audio information for the community and voluntary sector.

Terry has experienced discrimination in the past and has also had bouts of depression due to negative past experiences and feelings of isolation. He has fears about losing his benefits by doing voluntary work. A few years ago he became involved in a social enterprise being developed by a disability charity and as a result of this project he was able to earn permitted earnings for a few months. Unfortunately the charity went into administration and Terry, along with other staff was made redundant from this role.

Terry is a firm believer in using his skills both for personal and social value. He believes that his skills and knowledge are very saleable but is uncertain about how to develop a business or self-employment opportunities whilst being on benefits. He received business buddying support from a local charity for blind people for about a year recently but feels that his business idea needs more practical help to develop, such as marketing and promotional support.

Terry believes in the concept of a social wage, whereby people on benefits can earn money on top of their benefit without having to commit to permanent employment. He believes that this option would be ideal for people in his situation who could gain self esteem, develop skills, benefit the wider

community and gain a little more financial independence without giving up the security of the safety net of benefit.

“I would love to run a successful business, but my condition is getting worse and I have access problems with things like transport, access to printed materials and inter personal communications. I don't think that the communication barriers faced by visually impaired people are tackled in an overt way by any agencies. A blind person misses out on many non-verbal and body language signals in meetings or communicating with colleagues or potential customers. I'd like to see this area addressed through training for both the blind person themselves and within organisations”

“Training around self confidence and assertiveness are often offered but no guidance is given about the nitty-gritty of dealing with non-verbal communication. How do you deal with it, has anyone thought about the solution? Missing out on non-verbal signals is a greatly over-looked area. It puts me at a disadvantage in employment situations. Blind people sometimes miss the more subtle things in communication such as personal presentation and dress code. The psychology services are “blind” to this issue. Visually impaired people are excluded because of communication at a distance. Email is handy but there still needs to be a detailed discussion about this type of barrier”

Case study 19

Joshua is 23 years old and he has a mild learning difficulty. Joshua has done various work experience and voluntary work placements during the past 5 years, mainly in shops and big grocery stores, but he has so far never been rewarded with a permanent salaried position. Joshua is a very quiet person and is aware of his own lack of confidence and assertiveness. His work experience placements have helped him gradually build up his self confidence as well as getting used to the employment environment and acquire some skills along the way.

However, the barrier which Joshua seems to come up against, time and again, is being able to sell himself in the recruitment process, especially at interviews. Having a hidden disability, Joshua feels that potential employers judge him negatively on the basis of his quiet personality. On one occasion during the action research phase, Joshua was turned down from the recruitment process of a large chain of DIY stores after taking an online personality test and on the basis of his results being told that he did not fit the profile of the company's 'top performing staff'. When he took the same online test a second time with telephone support from the recruitment staff he got different results but was still turned down on the basis of his personality still not fitting the required profile.

Joshua's self confidence was very dented by the experience and he recorded feelings of anger and frustration. He expressed that perhaps he should have lied on the test or told them what he thinks they want to hear. “I am being discriminated against because I am shy and lack confidence”

On other occasions during the action research phase, Joshua successfully got to the interview stage but this time was turned down at interviews because he lacked self confidence and the skills to sell himself, even though on paper his CV demonstrates a strong commitment and some useful past experience in terms of on-the-job work experience. Joshua remains committed to his job search and continues to do voluntary work. His Disability Employment Advisor is referring him to a sheltered business company where he may be given a fairer chance to prove his value to an employer without being knocked down at the first barrier.

Questionnaire Phase 2

Phase 2 of the Questionnaire took place simultaneously to the end period of the Action Research phase and was designed to try to make a broad sweep of issues with a particular focus on good practice in service provision. Respondents were asked to highlight three examples of good practice from employment support agencies that they have directly observed or experienced; three areas where they might have been supported more; an open question asking for ideas to improve existing services; an open question to identify barriers preventing people from gaining employment and a final question on what should be done to remove specific barriers.

Questionnaire 2 therefore gave us an opportunity to spread the net one final time by way of identifying barriers not hitherto discussed but also to contribute to the conclusions process in the final report in terms of focussing constructively on good practice. Some of the people who completed Questionnaire phase 2 had previously participated in one or both of the two previous phases, a number were new people who had not participated in the research previously. Here are some of the comments selected from the responses to Questionnaire phase 2:

Support that people valued:

“The agency helped to instil confidence in me”

“Training in a sheltered factory”

“The agency helped me to fill in application forms”

“Looking for vacancies at job club. Help with application forms. Help with a C.V.”

“Applying for and making a business case and providing links to organisations who offer work preparation programmes”

“I am hoping to rebuild my confidence by doing voluntary work with some training“

“It’s also the social aspect, socialising with people in the same situation gives you new confidence as well as sharing information”

“The agency helped me to use the internet”

“The agency was prepared to help sort problems out if there is work I have found but barriers in place”

“It’s useful to be shown where to look for work, how to fill in CVs. The experience helped me to update my own knowledge”

“Attending a support service helped me to work out if I can do things, such as building my self confidence – I found group experiences useful”

How an agency could have helped me more:

“Employers should be more flexible about people having to take time off for hospital appointments, I wouldn’t mind losing the money as long as I still had a job”

“Agencies only address the obvious access barriers – the things that the law requires. They neglect to address less obvious barriers which can impact very significantly, such as lighting levels and for me, the chemicals used for cleaning whiteboards”

“Someone to help me get into a job – help with application forms, interviews or in a job club”

“Personal contact with benefit advisors instead of dealing with things over the telephone”

“I found it useful to have support at an interview I attended. So more of that personal one-to-one support”

How I would improve employment support & training services:

“A more comprehensive assessment of individuals and an understanding of where there are problems and how to overcome problems, e.g. information about allergies and radiation sickness”

“Benefit advice and not having to argue for benefits. Removing the traps to being able to work. There are too many regulations and not enough incentives”

Specific barriers:

“References – it’s difficult to get references from my former employers. My employment record spanned about 30 years without a break until I was made redundant. But then I became disabled and couldn’t work for a few years; in which time both of my former employers went out of business. So now it’s impossible to get references because the companies that employed me no longer exist. The gap in employment at my age (59) becomes a barrier, as I would need retraining. There needs to be some way for people in my position to get references, perhaps from a job club or a training agency”

“I’d prefer to be on income support than JSA because it would get me better access to support”

“Employers discrimination on age grounds – the law should be enforced and there needs to be more awareness”

“Barriers start in segregated education and then disabled school leavers are plunged into the employment market without preparation. There should be government targets for academic achievements in special schools”

“Finding something suitable”

Focus Groups

Also in this final phase, two focus groups were held at Birmingham Disability Resource Centre where local service providers were invited to discuss the key points raised by the research as a whole. Two additional meetings were held with officers from Birmingham City Council Employment Preparation Team and a visit was also made to Shelforce, a supported business in North Birmingham.

Key Findings and Recommendations

The findings of this research were wide ranging and of high qualitative value in terms of impartially recording the experiences and perceptions of disabled people in Birmingham who are either economically inactive or looking for employment and / or related opportunities.

Key Finding (1):

Disabled People want to try out work but experience restrictive regulations within the benefits system.

96% of our questionnaire respondents were in receipt of welfare benefits, 81% said that they felt they could do some form of work given the right support or flexibility, yet 64% of our questionnaire respondents said they were not engaged in any form of training or work experience related activity at the moment. 38% of our questionnaire respondents said that getting a job was their number one ambition in life.

88% of disabled people participating in the Action Research phase said that they value opportunities which allow them to increase their employability, for instance by learning new skills or acquiring self confidence through voluntary work, work experience and permitted earnings (activities which are referred to as 'soft outcomes'). Every person in this group said that negative experiences and perceptions about benefit regulations act as a barrier for people when they want to engage in such activity.

In spite of strong evidence that disabled people want to work, the benefit system is a barrier in terms of restricting people from increasing their employability. The qualitative evidence from the research has identified several examples of good practice where disabled people have gained skills and increased their employability through 'soft outcome' activities.

Recommendation:

A consultation should take place between Jobcentre Plus, DWP and other agencies around the development of more activities and opportunities referred to as 'soft options'

Accurate information about existing schemes such as permitted earnings should be more widely promoted to job seekers and to potential supervisory agencies. There should be a planned, across-the-board reduction in the application of restrictive rules which discourage engagement in 'soft option' activities and a systematic promotion of incentive based benefit rules, such as being able to earn on top of benefits, having benefit security and having access to other support whilst engaged in beneficial activity. The consultation should aim to produce firmer, more easily understood and universally applied guidelines around the benefits of soft option activities. The consultation should aim to produce more tangible methods of measuring the developmental

benefits of these types of engagement, but within a flexible framework, which takes account of the diversity of the disabled community.

Key Finding (2):

Disabled people are more likely to enjoy fulfilling and sustainable employment when they work for a flexible and supportive employer.

89% of disabled people participating in our research said that issues around flexibility in employment (working hours, policies and procedures) are important factors in determining whether they will be successful in gaining and sustaining work. During the Action Research Phase participants expressed interest in forms of work which allow them greater flexibility in choosing their own working conditions and environment, such as self employment, freelance and sessional work, home working and small business or social enterprise development. In the qualitative evidence there are several examples of good practice where disabled people said that their employment had been successful and sustainable because of the flexible support offered by an employer. However, disabled people also told us that they find it difficult to get specialist advice and support around flexible employment options such as remote working or self-employment. The qualitative evidence contains many examples where employers do not offer reasonable adjustments. There are also examples of good employment practice, such as within Birmingham City Council which could be shared with external employers.

During two of the service provider Focus Groups, discussions took place around the perceived lack of confidence in the Two Ticks certification scheme, with professional workers who have direct experience of the scheme agreeing that there are flaws and weaknesses in it's administration. Observations included the perception that there has been a lack of commitment to the scheme and that certificate holders are not re-assessed on a regular basis.

Recommendation:

Wider support to individuals wishing to explore flexible ways of working, more training and information for businesses and employers linked to a quality mark 'with teeth'

Funding agencies should support projects that provide a range of specialist advice and guidance services to disabled people wishing to develop flexible ways of working. Such services might include business mentoring and buddying whilst also linking to wider support services such as Access To Work. Existing support services could be more widely publicised. The idea of a quality mark to demonstrate good practice amongst service providers and employers is perceived to be a good one but should be expanded and linked to training provision and other types of support for all agencies and businesses. Employers need to grasp both the business as well as the diversity case for greater flexibility in the workplace. A quality mark system needs to enforce this concept and needs to be more effective. Audits need to be more systematic and linked to a referral system for employer training.

There should be a system for removing the quality mark if employers fall down on their commitment. The quality mark could be linked to an online forum or newsgroup for sharing good practice amongst service managers. There should be a pilot study through which agencies with good practice to share, such as Birmingham City Council, can impart knowledge to external employers around things like reasonable adjustments and flexible working practices. A pilot project could be designed to support employers to prioritise sustainable employment for disabled people.

Key Finding (3):

Communication support is vital to many disabled people and a major barrier exists where it is not provided

20% of disabled people participating in our research told us that they have a sensory impairment and 63% of the overall total of people who filled out questionnaires said that communication support is important to them. Qualitative evidence from the Action Research Phase reinforces the finding that disabled people in this group experience a significant barrier if interpreters, communication aids or alternative formats are not supplied by service providers. During the action research phase of the research a group of 5 deaf job seekers told us that their common experience was that employment related service providers, including statutory agencies, do not provide British Sign Language interpreters even when the individual is a regular service user and is attending by appointment. Good examples have been cited, such as in the Employment Preparation Team at Birmingham City Council where staff with BSL interpretation skills are employed on each floor of the office.

Recommendation:

All agencies providing employment support services in Birmingham should be encouraged to review their provision of interpreters, accessible formats and other communication aids.

A local scheme should be supported to train more people to a recognised standard of BSL and other commonly used languages and systems of communication. Every service provider should be encouraged to employ people with communication skills or to make training available to existing staff. A more comprehensive database of freelance workers with communication skills could be coordinated between relevant agencies such as RNID, BID, RNIB, People First and other specialist groups.

Key Finding (4):

Many disabled people have expertise and skills in delivering equality or access advice but are not rewarded for their contribution

20% of disabled people participating in our Action Research told us that they occasionally or frequently give their own time free of charge or for payment of expenses only, to deliver talks and presentations to organisations such as

schools, colleges and youth clubs around disability equality and awareness issues. Our interviewees told us that they gain a high degree of social value from these activities, they feel they are contributing to their community, they are learning skills and self confidence and they are helping to raise awareness and change attitudes about disability. Our interviewees also told us that they would like to receive some form of payment for their work.

Recommendation:

Disability Ambassadors—acknowledging the value of disabled people’s knowledge and participation

There is potential to develop a scheme where disabled people are trained to be Disability Ambassadors, individuals who can go into some of the agencies mentioned above to raise awareness and promote equality around disability. The Disability Ambassadors should be paid a sessional wage allowable on top of benefits in negotiation with the Department for Work and Pensions along the idea of a social wage.

Key Finding (5):

Barriers around independent living

28% of disabled people participating in our Action Research Phase told us that some of the biggest barriers to employment are caused by not having enough support with their independent living needs. One disabled person told us that she has had to struggle to obtain Direct Payments, funding she can now use to pay her own support workers. Another disabled person told us his life is in a rut and he feels overwhelmed by red tape. The qualitative evidence around independent living needs from our Action Research phase was very high with a disabled worker from an Independent Living support service describing how the barriers to employment start “before the disabled person even reaches the ladder”. There is evidence in the research that many agencies in the city are providing different aspects of the support that disabled people need but greater coordination is needed.

Recommendation:

A holistic, person-centred approach across all services

A city wide Key Worker scheme should be developed and coordinated between existing services who offer support on both independent living and employment advice and guidance. The Key Worker could offer a service that bridges the gap between independent living issues and training and employment opportunities with the additional availability of more specialist support in either area. The scheme would encourage a holistic approach and greater connectivity between service providers. Examples of good practice such as ‘person centred services’ should be developed within the modernisation of adult day services in Birmingham, with greater attention to the key transitional processes that affect many disabled people, such as the

transition from school to adulthood and the rehabilitation process following a new impairment or a medical or health related crisis.

Acknowledgements

We would like to thank the following individuals for their participation and / or support in this research project. We sincerely apologise if you have been not been acknowledged:

M Ahmed	Tanvir Ahmed	Mobeen Akhtar
Jenny Austin	Anne Bailey	Shellyann Bacchus
Erica Barnett	David Barnsley	Christine Bean
Pete Beard	Alex Bergman	Andy Beaton
Annette Bick	Iain Biddle	Annette Boaler
Paul Boaler	Fiaz Bokhari	Shazad Bokhari
John Boular	Chris Boyce	Paul Brennan
Sophie Broadway	Kate Brookes	Paul Brookes
Iona Burchell	Cynthia Brown	Jerome Chen-Bacchus
Francis Clarke	Ray Brookes	Jon Coleman
Caroline Connolly	Shirley Cooper	Carole Cunningham
Michael Day	Wendy Deffley	Jane Dickenson
Sue Dickins	John Doherty	Sue Easthope
Lynn Edwards	John Ellis	Graham Featherstone
Andrew Fellows	Sharon Gibbs	Stephen Gill
Alan Goldsmith	Ray Gormley	Dave Gray
Daniel Harris	William Harris	Sue Harvey-Hall
Catherine Hawkins	Sue Hawkins	David Homer
Margaret Hood	Lynn Insley	Zayd Iqbal
Cora Jones	David Jones	Greg Jones
Karlean Jones	Ronald Jones	Ben Kelly
Thomas Kelly	A Khan	Michael Khan
Rehana Khan	Fatima Khatun	Alison Leach
Christopher Lees	Jacqui Lewis	Robin Lodge
Mark Lynes	Jaz Mann	Juliet McCalla
Pauline Miller	Islam Mohammed	Philip Moore
Rob Moore	Peter Moran	Robert Mottram
Steve Mullan	Debbie Nunn	Katy Owen
Patricia Penado	Mohammed Quayam	K Randan
Aron Reynolds	Sabrina Richards	Hayley Ridewood
Dave Robinson	Derek Rogers	John Ruddock
Nuala Ryan	Michelle Sandford	Isobel Shaw
Amarjit Singh Sembi	Alison Simkin	Louise Simmons
C Smith	Sue Smith	Tracey Sollis
Christine Spooner	Dean Stafford	Paul Stevens
Simon Stevens	Dave Stinson	Christine Sumner
J Taylor	Anne Tebbut	Judy Thomas
John Tidy	Sam Tomlinson	Sandra Troth
Mohammed Vaseem	John Verma	Barbara Ward
Jackie Warrel	Katie Webb	Lisa Welsh
Steve Whitehorn	Lynn Whyley	Malcolm Wild

We would also like to thank those individuals who took part but did not wish to be acknowledged in name and also people who contributed comments and feedback from focus groups and workshops at a number of public events.

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Thank you to everyone who has supported and participated in our research project. Thanks to our research facilitator Pete Millington and to our funders, Birmingham City Council and the European Social Fund.

Barriers and Perceptions has been funded by:

Birmingham City Council

and

European Social Fund

DISCLAIMER:

The views expressed in this report are not the views of Birmingham City Council or Birmingham Disability Resource Centre, but those expressed by participants and summarised by Birmingham Disability Resource Centre. Birmingham City Council is not responsible for errors or misrepresentations.

Respondents in the research have signed consent forms to allow their views to be published but have been assured anonymity. Every effort has been made not to identify individuals, whether they be respondents or third parties identified by respondents in questionnaires and interviews.

Appendix 1

Research Questions

Contact details

Current employment status

I am in receipt of a benefit and not working

I am in receipt of a benefit and taking part in voluntary work, permitted earnings or something similar (please indicate which)

I am on a training scheme or a course (yes / no)

I am in employment (yes / no)

Age

Gender

Please describe your ethnic group

I identify myself as a disabled person (yes / no)

I have the following access needs which must be considered should I participate in the future activities of this research project (e.g. large print, loop system, ramped access, BSL interpreter, etc):

Your past experience of training, job searching and employment

Have you worked in the past 3 years? (Yes / No)

Tell us about the work or jobs you have done in the past:

Why did you stop doing this work?

Have you been out of work in the past 3 years? (yes / no)

If so, how long for?

Do you believe your period of not working was directly related to being a disabled person? (yes / no)

If so, can you tell us why? For example were you unable to work because of your medical condition, or negative past experiences of being employed, or an experience of discrimination in the past, or the fear of losing your benefits, or concerns about access barriers and support issues in the workplace, or something else?

Have you been in receipt of Incapacity Benefit (or a similar benefit) in the past three to five years?

Did you find benefits adequate to live on? (yes / no)

What were your feelings about being on Incapacity Benefit?

Did you feel that the description of being 'incapable of work' was an accurate description of your circumstances and your abilities? (yes / no / expand if you want to say more)

Whilst you were in receipt of Incapacity Benefit (or another similar benefit) did you ever believe that you could do some work with the right support or changes to the system? (yes / no)

Give some examples of the work you wanted to do and the support or changes which could have helped you?

Which of these issues are the most important things for you in deciding to come off benefits and trying to find work:

- I want to have more money
- I want to have a rewarding career
- I need something to do with my time
- Pressure from my family or friends
- Pressure from government agencies
- Encouragement from agencies
- Fear of losing benefits
- Stereotypes in the media
- My condition has changed
- A new opportunity has arisen

Tell us about any training courses or employment support you have attended or received in the past 5 years

Which of these was the most useful and why?

Tell us about your plans and ambitions in the next 2 years?

Are you getting support from a local employment or training support agency in achieving your goals? (yes / no)

Please tell us the name and contact details of the employment or training support agency

Do you think that the employment or training support agency understands your disability? (Fully / partly / not at all)

Are your access and support needs being met or considered by the support agency? (Fully / partly / not at all)

Do you feel the support agency is pointing you in the direction that you want to go in? (Fully / partly / not at all)

Overall, how do you feel about the support you are getting? (Very happy / satisfied / not satisfied)

Please add any further comments about the support you are receiving from an employment or training support agency. If you have ticked that you are not satisfied with any of the things in questions 3.3 – 3.6, please give some specific examples of why you aren't satisfied or suggestions on how things could be better:

Can you give us an example of good practice from a support agency, perhaps how someone has supported you with an access barrier or has impressed you with a positive perception?

Can you think of an example of poor practice from a support agency, perhaps when someone has overlooked your access needs or made assumptions about you?

Which of these access issues will influence whether you are successful in finding a job?

Physical access
Communication and or sensory support
Personal support / assistance
Accessible equipment
Support to access and use ICT
An understanding
support worker
Flexibility in what sort of job I can do
Supportive colleagues
Positive procedures
that support my rights
Other people's perceptions
My own perceptions

Do any of the following wider / external issues affect your ability to find employment or access training support?

Language

Housing

Transport & mobility

Childcare and / or caring

Migration and asylum issues

Independent living needs

Income considerations

Other (please tell us):

Identify three main barriers that have stopped you from finding sustainable work in the past and may prevent you in the future?

What could or should be done to change these barriers?

Overall, do you believe that the support agencies who are helping you to find work have your best interests at heart?

If not, can you explain why you have suspicion, distrust, cynicism or doubt?

Do you think that the training agency has a positive perception of you?

If you think they have a negative perception, please tell us what you think their perception is and how you feel as a consequence?

Do you wish to add any further comments, suggestions or observations about the barriers and perceptions that you have experienced or are experiencing in your search for work and in the support you receive?

Which of the following barriers and / or perceptions do you most commonly experience as a disabled person?

Many every day objects are not designed for my use

People do not listen or try to understand what I am saying

People do not treat me as an equal

People do not respect me

People do not understand the impact of my impairment

People talk down to me or treat me like a child

I would get on more in life if I had an advocate or mentor

Most information is written in jargon I don't understand

Other people are afraid or intolerant of my impairment

I often have problems gaining access into buildings

Public transport is frequently inaccessible to me

It is difficult to get information in my chosen format

Other people do not accept that I am a disabled person

I feel that I am treated like a medical condition not a person

If there are things that you experience which are not on this list, please explain the barrier or perception and how it affects you on a daily basis

Would you consider taking part in:

A six month Action Research project exploring some of the barriers and perceptions which you have identified?

A follow up to this questionnaire next year (yes / no)

If you are interested in taking part in either or both of the future phases of this research project, please tell us one main barrier and one main perception that you would be interested in exploring further and also think about what can be done to make a change to each issue:

a) Tell us about a barrier you would like to change:

Tell us who should do something to change this barrier and what they should do:

Tell us what you could do yourself to change this barrier:

b) Tell us about a perception you would like to change:

Tell us who should do something to change this perception and what they should do:

Tell us what you could do yourself to change this perception:

If you would like to take part in the follow-up questionnaire next year but do not have time to commit to the more in-depth Action Research phase, it would still be useful to our research project if you kept some brief personal notes or recordings about the issues that you have identified above. This way we can measure whether individuals have been able to influence or change current practice amongst employment support agencies between now and the next questionnaire.

Things you might make notes about:

- Identify a perception or a barrier
- Think about how the perception or barrier can be changed
- Try out a simple strategy to bring about a constructive change
- Does anyone else support your strategy?
- Are there cost or other factors to be considered?
- Do things happen within a reasonable time frame?
- Do you experience opposition to the change and why?
- After the change has taken place, has it improved the problem?
- What do others think about the change?
- Do you need to change your strategy or design a new one?

Statement of Consent

Name

I have read the Data Protection, Confidentiality and Disclosure Policy at the start of this Questionnaire and I understand that some or all of the information I have given on this form will be published in an Action Research report written by Birmingham Disability Resource Centre.

I understand that I will not be personally identified in the report next to the information I have provided but, if I choose, I will be acknowledged for my participation in a separate section of the report.

I agree with the Data Protection, Confidentiality and Disclosure Policy and subject to it's conditions I give my consent for Birmingham Disability Resource Centre to use the information in my Questionnaire for the purposes of producing the Action Research report on barriers and perceptions facing disabled people who are seeking employment:

Signature or Identification mark

Date

Please indicate whether you want to be personally acknowledged in the published report (yes/no):

Appendix 2

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Glossary

AIDS	Acquired Immunodeficiency Syndrome
ASDAN	Award Scheme Development and Accreditation Network
BCC	Birmingham City Council
BDRC	Birmingham Disability Resource Centre
BME	Black Minority Ethnic
BSL	British Sign Language
CAB	Citizens Advice Bureau
CD	Compact Disk
CV	Curriculum Vitae
DDA	Disability Discrimination Act
DEA	Disability Employment Advisor
DJ	Disc Jockey
DLA	Disability Living Allowance
ESF	European Social Fund
GCSE	General Certificate of Secondary Education
HIV	Human Immunodeficiency Virus
HND	Higher National Diploma
IB/ICB	Incapacity Benefit
ICT	Information Communication Technology
JSA	Job Seekers Allowance
LSC	Learning and Skills Council
NI	National Insurance (number)
NVQ	National Vocational Qualification
OFSTED	Office in Standards for Education
PA	Personal Assistant