Cornwall People First

Work In Progress

An Inclusive Research Project

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The research sites

Cornwall Works for Learning Disabilities

Pure Innovations

The Rose Project

miEnterprise

Advisory Panel

Val Williams

Molly Mattingly

Fiona Gendall

Frank Baker

Theo Blackmore

Kathy Melling

Ex co-researcher

Jeff Davies

Research supporter

Sally Scott

Norah Fry Research Centre

Val Williams

Kelley Johnson

Kerry Ford

Work's For Us DVD

Dan Mallet

Brett Harvey

Sammy Avery

Giles Worley

Nigel Fox

Trevor Andrew

Liskeard Museum

No 18 The Coffee House

Simon Harvey

And the very lovely Ava and Leo Mallet

And not forgetting all the participants who took part in the research.

Copies of the full report can be downloaded from the Cornwall People First website. Copies of the DVD that accompanies this report are available on request from Cornwall People First.

Glossary: Explanation of terms used in this report

We have used the term *learning disability* throughout as opposed to *learning difficulty.*

Co-researchers: people with learning disabilities employed in the research team.

Inclusive research: a range of research approaches that involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users (Walmsley & Johnson, 2003; 10).

Job Coach The most common job title for those people who are employed by a Supported Employment Agency (SEA) to support people into work and at work is *job coach.* Although not all the SEAs we visited used this term we have employed it throughout to avoid confusion and protect the confidentiality of those to whom we spoke.

Job seeker: A person who is looking for paid employment and being supported by an SEA to do so.

Participants: All those people who were interviewed by the research team throughout our project.

Supported Employment Agency: service that specialises in working with disabled people to help them find and keep paid work.

Work in Progress: Executive Summary

- 'Work In Progress' was an inclusive research project (2010-12), which aimed to find the best ways for people with a learning disability to be supported into paid employment. It was funded by the Big Lottery.

- The research was carried out at Cornwall People First, with four paid posts for co-researchers who had a learning disability. They all had experience of using supported employment agencies (SEAs), and they were able to see things from the point of view of the people with learning disabilities whom we interviewed. That is what makes this project unique.

- We interviewed sixty three people, including clients of SEAs, family members, job coaches, managers, colleagues and employers, in four different settings. Each SEA followed a slightly different model, although all used job coaches (see glossary). The models included a college-based course, as well as an SEA supporting people to set up their own businesses.

- SEAs often had short-term funding, and were under threat of closure. That was one of the biggest problems for everyone.

Why work?

> *"I want to be able to get up in the morning and think "OK, I'm going to be coming into work and doing something – meeting people, not just sitting here.'" [Participant]*

People with learning disabilities said they wanted to work for the same reasons as everyone else, to earn money – but also to have something to do in their lives, meet people, keep motivated, and be part of things. But we know that only one in ten people with learning disabilities have any type of paid employment. Times are tough with financial cuts in 2010-12. One person with learning disabilities said: *"jobs are like hen's teeth."*

- One of the main things that put people off seeking work was the benefits system. They thought they would be worse off if they worked, and they were worried about getting into trouble over their benefits. People told us that having clear and accurate 'better off' calculations was helpful.

- Support from families was important for those who were positive about seeking work.

Applying for a job

> *"It helped me that my job coach was with me at the interview, I felt less nervous." [Participant]*

- Job applications were often difficult, made worse by online systems. Most people had poor qualifications, so would not get to the interview stage without support. SEAs sometimes helped employers to use working interviews, work trials or creative events like 'Dragon's Den' to recruit people with learning disabilities.

- People with learning disabilities said it was good to have support at interviews.

- Families and people with learning disabilities said it was important to have support for work at an early stage, with schools and colleges helping people to find a job. They felt that people lost hope afterwards.

- There were different models of support to help people find work in the SEAs we visited. People found it useful to have a learning group or a job club, so that they could connect with others seeking work. This was also important in one SEA where people were setting up their own businesses.

- People with learning disabilities wanted to get a 'foot in the door', even if that was through voluntary work. But SEAs often said it was not good for people to have long, unpaid work experience placements.

The role of the job coach

> *"My person-centred planning meeting …was very, very good. We were talking about how I'd get on…and I'm doing really, really well."* *[Participant]*

- The job coach is the key figure for the job seeker as they move through their journey into the world of work. The main responsibilities of a job coach are to support adults with learning disabilities from the referral stage through to all aspects of employment including: helping an individual to seek appropriate employment; supporting people when they are completing applications, preparing for interviews and even attending interviews if required; teaching them how to do the job through systematic training; providing the right level of support for the individual to ensure that they stay in employment (BASE).

- Many people had very good experiences of having a job coach. It was especially good in one place, where job coaches worked through person-centred planning.

- But some people told us that they were confused about what a job coach could do. They sometimes felt let down by job coaches, but felt they had to be grateful. It was best when the job coach and their client had a clear written agreement to clarify roles.

- Some people had very strong ideas about what type of work they wanted to do. We called this their 'tunnel'. It was important for job coaches in SEAs to strike a balance between job matching to find the exact job someone wanted to do, and being realistic about what work was available.

- In three of the SEAs, job coaches worked with employers to 'carve out' a job that would suit the person with learning disabilities, which was seen as useful.

- People sometimes felt under pressure to find a job, because of the job coach and SEA. That was not always helpful.

At work

> *"I work in the kitchen and the lady I work with she's absolutely brilliant. I couldn't wish for anybody better."* [Participant]

- Job coaches generally kept in touch with people when they were in a job. People liked that, and wanted to know they still had that contact. But job coaches also thought it was important to 'fade' their own support, and to help other work colleagues to take over. That could lead to a better team approach at work.

- Ongoing support was important for some people, even after they got a job. They said it was helpful if they could contact the SEA and get help if they had a problem. One SEA managed this by having a monitoring team, and others encouraged people to get Access to Work funding for ongoing support.

- One SEA kept in touch with former clients, after they had got jobs. They were encouraged to give peer support to new job-seekers.

- It was felt important to put more effort into sustaining a job. When someone had lost their job, they found there was no support from the SEA, leading to further personal problems for them. Career progression was important for people, but not often supported.

Recommendations

Recommendations for policy makers

- **The Department for Work and Pensions should work with the Department of Health to ensure that sustainable long term funding is put in place for SEAs, so that they can offer stable support for employees with learning disabilities.**

- **Supported employment as a whole should be more widely promoted, especially for young people learning disabilities at transition. There should be a nationally recognised pathway, so people are aware of what supported employment can offer.**

- **The job coach provides the link between the SEA, job seeker, families and employers. It is important that they are supported and valued. Widely recognised job coach standards would ensure that all stakeholders know what they can expect from a job coach.**

- **Local councils should ensure that workers with a learning disability can use free bus passes during peak times.**

- **Job seekers should be seen as customers, able to choose the support that suits them. In each area, there should be a range of SEA models, with self employment and creative support for people with more severe disabilities.**

Recommendations for supported employment agencies (SEAs)

- **SEAs should provide a clear and consistent approach to guiding people through the benefits maze. In partnership with the benefits agency, a named specialist within the benefits system should be available, who has experience of working with people with learning disabilities.**

- **SEAs should organise groups where job seekers can come together and offer each other peer support. Peer support for those in work should also be provided.**

- **Agencies need to be available to support people through a job breakdown.**

- **SEAs should share good working practice. They should work together to increase the chance of individuals getting the support that is right for them.**

Recommendations for job coaches

- **A written agreement between job coach and client should ensure clear roles and boundaries, and guard against clients becoming over dependent.**

- **Specialist job coaches with experience in particular areas of work could be matched to particular job seekers.**

- **Job coaches should take a person centred approach when getting to know their clients, and should believe that everyone who wants to is able to work. Their role should include:**

    - **Offering support throughout the process of finding and getting a job**
    - **Ongoing support to sustain jobs and encourage career development**
    - **Cold calling and promotion to raise awareness with employers**
    - **Creative and innovative ways to support those with high support needs, including the use of photographs and social stories**
    - **Recognising and maintaining motivation in clients**
    - **Liaison and communication with all stakeholders**
    - **Travel training for job seekers when required**

- **Job coaches should work with families through parent forums, home visits and regular contact, to help them to see the benefits of working and reassure them about the financial implications. This should be done with the consent of the job seeker, and without undermining their independence.**

- **The core way of working should still be one to one visits with the job seeker.**

Recommendations for employers

- **Employers should promote lift-sharing schemes.**

- **Working interviews should be used where possible, to give applicants with learning disabilities a better chance to show what they can do.**

- **Employers should make better use of the Access to Work scheme.**

Contents

Chapter 1

Introduction and Methods

Background

The problems faced by people with learning disabilities in gaining paid work are well documented (Beyer *et al.,* 2004; Emerson *et al.,* 2005). Research has also shown consistently that supported employment is important when people with little or no experience are moving into the world of work (Forrester-Jones *et al.,* 2004; Jahoda *et al.,* 2009; Beyer *et al.,* 2010). However support is sketchy and varies from region to region with no consistency of delivery (O'Bryan *et al.,* 2000; Jones *et al.,* 2002), although much of this may be explained by differences in appropriate funding streams across the country. There has been very little research, however, about the point of view of people with learning disabilities themselves. 'Work in Progress' was set up to see if the way in which supported employment agencies operated made a difference to those receiving the service and what they thought worked well. Not only were we comparing supported employment agencies geographically but we also aimed to compare different models, in an attempt to identify what worked best from the point of view of their clients.

The issues in supported employment also affected the research team, which included four co-researchers who all had experience of using similar services. There has been very little inclusive research to date in the area of employment, (see Ridley & Hunter 2006), although it has been identified as an area of interest by people with learning difficulties (Williams et al 2008). That was the gap which 'Work in Progress' aimed to fill.

1.1 Aims and preparation

'The aim of 'Work in Progress' was to find out what strategies work best when supporting people with a learning disability into employment. We were particularly

interested in identifying barriers and solutions and finding innovative ways of supporting people into work. 'Work in Progress' was planned and funded as an inclusive project, in which people with learning disabilities would play key roles in leading the research; following the appointment of the four co-researchers, they were involved in every aspect of the process . The team also included a research co-ordinator and a supporter, with consultancy support from Norah Fry Research Centre at the University of Bristol. For more details of the inclusive approach, see Appendix 2.

None of the co-researchers had previous experience of research, and the first six months of the project were largely spent training and learning about supported employment. There was an emphasis on interview techniques and practising with each other. We received research methods and interview training with people with learning disabilities from Norah Fry, as well as advice and guidance from staff there who were experienced in inclusive research.

During the preparation stage, we recruited and had the first meeting of our advisory group, consisting of people from national agencies, the Valuing People support team, and champions of employment for people with learning disabilities. The advisory group met four times during the project.

One of our first tasks was the literature review (see Appendix 1). We took each article and went through it with the team and then put it into 'easy read' language, using pictures. One of the most interesting aspects of this work was that it enabled the co-researchers to relate to what other people had found out about supported employment, and to compare that with their own views and experiences.

1.3 Telephone interviews

The first stage of the research consisted of a telephone survey, in which we aimed to find out more about the wider picture of supported employment services, and to select interesting examples for further interviews. Telephone interviews were carried out with six employment agencies, selected to try to represent the spread across geographical

areas of England, different models of support and size of the agency. The agencies were selected largely with advice from our project advisory group.

Table 1: Organisations in telephone interviews

Telephone Interviews	Support	Model	Funding	No of people signed up in last 12 months	No of people supported into work in last 12 months
Pure	Learning, physical, sensory impairments, mental health, looked after children.	Job coach/Project Search	Local Authority/ Government	300	28*
Progress	Learning, physical, sensory impairments, mental health	Job coach model	Local Authority/education/ health.	300	60
Linked	Learning disability	Job coach model	Local Authority/personal budgets		40
miEnterprise	Learning disability	Micro enterprise	Personal budgets		12
Rose	Learning disabilities	Classroom based. Job coach	Local Authority /college/lottery		35

		model			
Welfare to Work	Learning, physical disability/ school leavers	Job coach model	Local Authority	80	23

*The figure of 300 represents clients of Pure across all projects which will include looked after children and mental health service users as well as people with a learning disability. Some of these people would have been in employment and receiving support. At the time of interview 28 people with a learning disability had been supported into paid work over the last 12 months for the first time.

From these interviews we learned that there were lots of different ways of working within a supported employment agency. The funding was very different within each site. The telephone interviews were recorded and transcribed and then we created graphic representations of the results in order to enable us to compare them easily, as shown in Figure 1

Figure 1

Graphic representation of telephone survey in progress

1.4 Data from Cornwall Works

Cornwall Works for Learning Disabilities (CWLD) was the local provider for supported employment. We planned to recruit 8 clients to the project, and to match each of them with a co-researcher from our team, so that they could be visited several times and develop a relationship. When matching co-researchers to participants we considered how they would relate to each other, as well as taking into account where in the county the participants were based. We decided that the co-researchers would lead the interviews, asking the core questions that we discussed together prior to any interview and letting the interviews develop as natural peer to peer conversations. The research co-ordinator and supporter were to follow up any interesting points and ensure nothing was overlooked, to ensure the richest data possible.

Over a period of 12 months we got to know our participants well and the relationship the co-researchers built with them meant we were able to get some telling and rich data, which we were able to produce as individual stories (available on the Cornwall People First website). The positive value of using an inclusive research approach was most apparent at this stage. The co-researchers were able to empathise with participants and share their stories so that friendships formed and participants were particularly open. This happened to a lesser degree in the other sites which we only visited twice as opposed to the numerous times we met with CWLD participants.

All interviews were filmed on flip cams (small pocket sized camcorders) which were easy to operate for all members of the team. Interviews were watched back and transcribed, largely by one of the co-researchers.

1.5 Research visits to supported employment agencies

While the Cornwall Works interviews were proceeding, we started the third stage of the project, in which we aimed to carry out two visits to each of three supported employment agencies, selected because of their creative or innovative approach. From the information in the telephone survey, we were able to identify SEAs which we thought to be particularly interesting. **miEnterprise** was chosen because a co researcher liked the fact that they helped people into self employment and seemed person centred in the way they approached things. **The Rose Project** was of interest to another co researcher who had been drawn to the job as co-researcher in the first place because he wanted to improve things for his own young children. Rose is based in a college and works largely with 16 year olds. **Pure Innovations Employment** had a Project Search scheme and was much larger than the other agencies, which made for an interesting comparison.

We sent information packs to all the sites and asked them to distribute them to clients who might be interested in taking part in the research. Although we asked that they be distributed widely and included stamped addressed envelopes so that potential participants could return them direct to the research team, that process did not entirely

work. As a result all our participants returned expression of interest forms through their agency and we were fortunate in recruiting almost exactly the target numbers of clients at each site: at miEnterprise we had five, Pure seven and Rose six clients. Ideally we would have preferred to contact potential participants directly ourselves but due to data protection restrictions were unable to do so. We were concerned that SEAs may have 'cherry picked' participants, however given the variety of information we collected we do not believe that this way of accessing participants has had an adverse effect on the findings. The people involved in interviews are shown in Table 2.

Table 2: People taking part in interviews

	Cornwall Works	Pure	Mienterprise	Rose	
Participants	8	7	5	6	
Family members	5	1	2	4	
Job coaches/Managers of SEAs/support worker	5 (plus one email contact)	8	3	4	
Employers	1	1	2	0	
Total	20	17	12	14	63

1.6 Data analysis

The data analysis stage posed the greatest level of concern in the team, as other inclusive projects have also found (Chappell, 2000). We decided to follow two approaches. One co-researcher preferred to simply watch the videos of the interviews, and to record their thoughts about them. The other method was essentially a thematic analysis, in which we went through each transcript and marked interesting parts with headings such as 'good support from job coach', 'barrier', 'motivation', 'colleague'. The transcripts were then cut up and put into file boxes similarly marked. We then went through each box and further broke down the headings into themes. We could quickly

see where sites were strong and/or weak within each theme, by the use of different coloured paper for each site.

Figure 2 Photograph of one of our major research themes

1.7 Reporting on the research

One of the decisions we had to make was whether to write all our reports in 'easy read', so that people with learning disabilities could understand them. We decided to write stories, as well as individual site reports, which would be easy to understand for all the participants. These were returned to the sites, and discussed with them.

In order to write the current report, the research co-ordinator had to take a lead. However, the themes have all emerged directly from the co-researchers' own analysis and experience.

The current report follows through the journey towards employment, with each chapter representing one step on that route. In each chapter, we will highlight both the barriers people faced and the solutions they told us about. As discussed in the literature review, much of the research about employment has taken a medical model stance when looking at barriers (McConkey & Mezza, 2001; Broad, 2007; Lemaire & Mallick, 2008),

in that it focuses on the problems of fitting individuals into traditional job roles using traditional recruitment methods. By contrast, this research followed the social model of disability, and focused on the barriers created by the system such as the benefits system, application processes and the gaps in supported employment provision due to inadequate investment and geographical inequalities. Therefore, there is consideration of barriers and solutions in each of the chapters. Our findings show that with the right support and understanding employers some of these barriers can be overcome.

The journey to employment starts in Chapter Two by considering what people with learning disabilities told us about why work was important to them, since motivation to work is the starting point. Chapter Three then presents the findings about how our participants were able to 'start out' on the route to employment, and Chapter Four looks at job search strategies they were able to use, mainly with the help of the supported employment agencies. Chapter Five deals with actually getting a job, including the application process, and Chapter Six is about the issues people faced in keeping a job. Chapter Seven presents what people told us about 'moving on'. Sometimes this was problematic, especially when they lost their job. However, this chapter also mentions career progression, achievements, and what participants want to do next.

Following the analysis and reporting, it was also agreed with our funder that we could create a DVD to highlight the issues in this report, so that it could directly influence other people with learning disabilities and their organisations. That work will enable the team to carry out further visits, promoting and publicising the DVD.

In this report, we reflect on some of the issues raised by the research by including examples from the experience our own research team had, in gaining and keeping employment. Those experiences are highlighted in 'Our experience boxes'. More reflection about the process of inclusive research is included in Appendix 2 at the end of this report. These are some of the ideas co-researchers had about their own experience of doing research:

"Sometimes you have to be patient and understanding as some people found it difficult to speak about their experiences. Prepare to speak to anybody and to travel. Learning about what research is. Be honest and open and if you got any problems we are here to help. Be there to support anyone who is struggling. Been able to do the research and knowing what you are researching about. Someone who is inquisitive and has open mind is a good thing. Having the confidence and be part of a team. Understand the job and be part of a team help each other we all agree. We all agreed working in a team with other co researchers we found it BRILLIANT." [From a discussion by co-researchers]

Chapter 2

Why work is important

This chapter will discuss why work is important to the job seekers that we spoke to and what kind of impact having a paid job can have on a person's life. We will discuss whether having a paid job is important to a person with a learning disability for the same reasons as it is to the rest of society. As outlined in the literature review, previous research has shown that work is important to people for financial reasons, to improve physical and mental well-being (Stenfert Kroese et al, 2000), giving people something to do and for social networking (Forrester-Jones et al 2004; Jahoda et al 2010; Beyer et al 2010, Chadsey & Beyer 2001; Jahoda et al 2008). In each of the following chapters, we will also mention the barriers that people told us about, and what they said helped break down those barriers.

2.1 Why do we want to work?

Before we carried out any research, the research team had a discussion about why work was important to us. We all had very similar responses.

Our Experience Box 1: Why work is important to us

"I like to earn my own money"

"I don't like being at home with nothing to do on benefits"

"I'd be lost with no work"

"It's who I am"

"To meet new people"

"I want to support myself and my children; I take pride in my work"

"I get to do things I wouldn't normally get to do"

"I want to be like everyone else"

Reid and Bray (1998), argued that for people with learning disabilities' "reasons for and motivation to work mirrors that of the general population"(Reid & Bray, 1998: 238). When we asked our participants, "why is work important to you?" the responses were mixed, although not dissimilar to our team's responses.

- **Something to do**
"I was just lounging around the house and I thought time to get off your backside and do something"

- **Money**
"To get money for my dream" "Well you need money to survive "

- **Purpose in life**
" I want to be able to get up in the morning and think ok I'm going to be coming in to work and doing something I like doing and meeting people, not just sitting here looking at four walls"

- **To be like everyone else**
"Everybody just wants to be normal and go to work like everybody else … it's feeling part of the community"

- **To meet people**
"As well as earning money you just get to meet more people"

- **To keep motivated**
"Keeps me motivated, something to do"

The most common response was that work was important because it was something to do, it is clear that for the job seekers we spoke to having structure and a day to day purpose was important. This was also a strong view of a manager of an SEA:

> *"Without supported employment they will either go into day services which isn't appropriate for everybody, or they will stay at home and become economically inactive." [SEA manager]*

Our findings support those of Reid and Bray (1998) in that work is important to people with learning disabilities for the same reasons as everyone else. This is why supported employment is important as it gives people the opportunity to move further towards social inclusion and increases their social capital as was suggested in the Marmot Review (2010). This is a well established view; in 1994 The Prime Ministerial Taskforce on Employment stated that:

"A paid job is important because it provides a means to earn a living. But a job also fulfils a variety of social functions. A job is one way of participating in, and contributing to, the wider community. It is important to a person's sense of identity, independence, and self worth" (PM Taskforce, 1994: 1).

2.2   Overcoming barriers: motivation

The motivation of the job seeker has been shown to be an important indicator of how likely they are to be successful in their job search (Hensel *et al,* 2007; Rose *et al,* 2010). Our research indicated that it was often difficult to maintain motivation over a long period of time.

Participant's story

Sam was a 25 year old who lived at home with her parents. She received support from her job coach to search for employment and also had great support at home from her parents and extended family. After having sent of over fifty application forms and received no response from any of them, she explained that her motivation to find work decreased: "*it gets me down yeah*"

During one interview in particular Sam got very emotional, it was clear that she desperately wanted to get a paid job and was finding it frustrating that nobody would give her the chance. When we interviewed one of Sam's family members, they said that "*she gets very depressed".*

The research team had a discussion about 'motivation', one of our team said that he thought that SEAs should prioritise helping people who were more motivated to find work.

> *"I think that if somebody isn't that bothered about finding work then they should concentrate on people who really want work". [Co-researcher]*

The research team all agreed that the majority of the participants we interviewed appeared motivated to find paid work, although there were exceptions to this:

Participant's story

Peter is a 21 year old and attends a day centre most week days, he enjoys going there and has a very structured week, he has organised activities on most days. When asked about working he was very dubious about giving up any of his weekly activities. He was unwilling to be flexible when it came to working on the days he had planned activities.

This could arguably be viewed as having lack of motivation or that for Peter getting a paid job wasn't a high priority. Another participant forgot to go to a voluntary job that had been arranged by his job coach to gain some work experience. Again this could be viewed as lacking in motivation.

Interestingly neither of these participants had found paid employment by the end of the interview stage; this supports the findings of Rose *et al* (2010), who state that the motivation of an individual is the biggest indicator of whether they will be successful in getting a job. Rose *et al* (2010) suggest that motivational strategies should be used by SEAs to retain and build up the motivation of their clients.

2.3 Overcoming barriers: Fear and misunderstanding of the benefits system

We have seen that people with a learning disability want to work for various reasons and yet only 10% of this group are in paid employment. Our findings show that people not only want to work but with the right support they make effective and reliable employees. In order to help them achieve this, supported employment agencies need to

be aware of the barriers facing people with learning disabilities when trying to enter the world of work.

Interestingly although money is not the main reason people want to work, the benefit system and the fear of being worse off is often cited as the main barrier to employment. The benefit system was cited as a barrier to employment for people with learning disabilities by the Radar/Remploy Taskforce Report (2006).

Participants in the current research said that, prior to getting employment, their main concern was being financially worse off in paid work. Additionally people spoke about the complexity of the benefit system and the fear of not being able to reclaim benefits should there be a job breakdown. One of our participants expressed a fear about getting into trouble with the job centre if she got paid work:

> *"If you have another full time job sometimes someone reports you, they going to report you to the benefits and the benefits could stop your money" [Participant]*

Previous research shows that people are usually better off working, but the perception of some of our participants was that they would suffer financially. Ten of our participants mentioned benefits as a barrier, with most of these being from one particular SEA who gave varying accounts of their experience of the benefits advice they received. This would suggest that there was no clear strategy or named contact to help people with their benefits. The remaining three SEAs had strong links with the benefits agency so that they were able to provide people with clear information and better off calculations. This appeared to work particularly well in one site where a specialist worker was seconded to the SEA and therefore was on hand to provide the information as required. This was difficult for the agency to organise but seen as a vital part of the service.

> *"We second a lady from welfare rights and it's a key role. We fight to keep her."*
> *[SEA manager]*

The job coaches we spoke to referred to the problems they had encountered from the families of job seekers around the fear of losing benefits. As we will see later on support from families is an important factor when predicting who is likely to get and keep paid work. Where there is fear around the impact on the household income if one member comes off the benefit system, families may not be as supportive.

Recommendation

- **SEAs should provide a clear and consistent approach to guiding people through the benefits maze. In partnership with the benefits agency, a named specialist within the benefits system should be available, who has experience of working with people with learning disabilities.**

Chapter 3

Starting Out

In this chapter we will look at the initial stages of becoming a job seeker for our participants. This will include how they initially got signed up to an SEA. We will also look at how SEAs start the planning process with clients. We will discuss the barriers that our participants faced when trying to get paid employment. We will also report on the view of other stakeholders. We will talk about strategies that SEAs have adopted to overcome these barriers and the views of our participants about what works best.

3.1 The first contact with an employment agency

People in this research told us that they were usually referred to an SEA through the local Job Centre or a social worker. However, there were other routes. For instance, the Rose Project is based within a college; therefore they also receive referrals through this channel (Havering College), and this addresses the needs of people during transition.

We know from talking to people that raising the expectations of young people is important when they come to look for employment.

> "*It would be better if before you leave college in that last year they do it then, get that job. So once you leave you've got a job to go to. Because once you leave there is not a lot of help then.*" [Parent]

Other participants told us they regretted not having employment support at an earlier age:

> "*I never had any support when I left school, not at 16 no I didn't, basically I was on my own.*" [Participant]

As mentioned in the literature review (Appendix 1) not enough is done to help young people into work (Foundation for People with Learning Disabilities, 2005).

One of the SEA managers also emphasised the need to work with people during transition:

> *"People should have a transition pathway, and by that I mean school, college, employment, like everybody else." [SEA manager]*

In one site people who used the service were already known to the manager. Supported employment was not a concept with which most of our participants were familiar. When we asked people what they expected from their supported employment service the common answer was 'I don't know'. We did not meet any one who had self-referred. Professionals we spoke to believed that the short term funding often associated with SEAs could in itself be a barrier. Often projects would end and people had to begin again looking for support. Several of the participants had been frustrated by this.

> *"Feels like a waste of time sometimes, have to start all over again when a scheme stops." [Participant]*

Different models were being offered across the country. The kind of support available to people was very much dependent on where they lived. One of our participants could have benefitted from support through a miEnterprise type agency. His needs could not be met by a provider whose funding depended on getting him into paid employment.

> *Mum: "I don't think he could do that* (go self employed), *...we talked about it last evening, you felt you couldn't cope with it.*
>
> *Participant: "If I had the experience then yes, I could do it....*
>
> *Mum: You would need lots of support, you know, lots and lots."*

We believe there should be a nationally consistent approach so people can access the sort of support that suits them.

3.2 Family involvement

The SEAs told us that the attitude of the job seeker's family was a key factor in the likelihood of someone succeeding in getting and keeping a job. Family members and job seekers themselves agreed:

> *"We don't give up in this family!" [Parent]*
>
> *"When (name of job coach) took over and actually got me to do it, I sat here and mum sat there and we both done it together" [Participant]*
>
> *"I just sit with him and help him. Help him with ideas that he's not quite thinking of. Remind him what he's done....It's just sit and listen and look after him basically" [Parent]*

SEAs tried to involve families at an early stage to ensure they were 'on board'.

> *"Because after all it's the parents that are going to be saying, come on get up for work………..We do make sure they are really involved, they are involved right from the beginning. They are not involved with the assessment; we do that just with the client. But at the interview stage they are fully involved and they have to sign all sorts of things. Now we can support someone in work, we can travel train them, but we can't get them up in the morning." [SEA manager]*

Our co- researchers agreed this was a good thing; however one of the co-researchers reflected on her own experience:

> **Our Experience Box 2: Why we should be asked about our parents' involvement**
>
> *"When my job coach first came to see me, he asked me in front of my mum and dad if I minded if they were there. I said no but didn't feel like I had much choice" [Co-researcher]*

3.3 Pressure

Among our participants there was talk about 'pressure' at different stages of their journey with an SEA. For one of our participants he felt that the SEA in itself was creating pressure on him to find a paid job:

"*I think I was under too much pressure with the scheme I was with*" *[Participant]*

Similarly another participant said:

"*I'm getting sick and fed up with people telling me go and look for a job*" *[Participant]*

These two accounts referred to the initial job searching stage. Interestingly pressure was also mentioned by a further two participants once they were in a paid job. Nigel hadn't worked in over 3 years. When he secured a cleaning job he was excited about getting back to work.

> "*There was kind of a little bit of pressure from my job coach, like oh you have got to be quicker. I thought hang on a minute, please let me do a good job ……just give me that chance…..I can't do things quick in about 2 minutes.*" *[Participant]*

The relationship between a job coach and the client was the key factor.

3.4 Overcoming barriers: early planning

People who did not know about supported employment had often had previous experience of trying to find a job through a job centre. The Job Centre system was not perceived as giving good support to people with a learning disability. People told us they found it to be a confusing and intimidating environment where there was little understanding of their needs.

> "*We had a lot of trouble trying to get Pauline on the right benefits. She was just on normal job seekers allowance and she couldn't cope with the different people she was seeing every time.*" *[Parent]*

This reinforces the idea that specialist SEAs are more effective for helping this group of people. However, even when they did come into contact with an SEA, job seekers sometimes showed that they had low expectations of their own abilities.

> *"I think I'd be more danger"* [Participant]

In order to build confidence, and heighten the chances of obtaining a good job match it is important that the job coach gets to know the job seeker well. This can be helped with early planning sessions that not only look at what kind of work a person wants but also their skills and talents so the job search can be widened if necessary. A person centred planning approach to this was used in one site which was found very useful by both participants and families.

> *Interviewer: "How did (name of SEA) help?*
> *Participant: By having my meeting...it was very, very good. We were talking about how I'd get on at (name of SEA), and I'm doing really, really well.*
> *Parent: I can't say enough about Person Centred Planning!"*

This meeting was also an opportunity for the job coach to be clear about their role and what the job seeker could expect from the service. One of the sites would use this time to create a written agreement between the SEA and job seeker outlining the responsibilities of both parties. As we will see below, without this discussion, some of our participants were unclear as to what they could expect from their job coach:

> *"I sometimes wonder when she's here, I sometimes wonder what are you here for you know."* [Participant]

Recommendations

- **Supported employment as a whole should be more widely promoted so people are aware of what it can offer.**

- **There should be a clearer path to supported employment with nationally recognised processes.**

- **There needs to be a major focus on providing employment support to those in transition.**

- **SEAs should take a person centred approach when getting to know their clients.**

- **SEAs should work with families through parent forums, home visits and regular contact, to help them to see the benefits of working and reassure them about the financial implications. This should be done with the consent of the job seeker, and without undermining their independence.**

- **SEAs need to be careful not to pressurize clients in a way that can have a negative effect on them.**

Chapter 4

The Job Search

4.1 Different models of supporting people to find work

The four SEA's that we looked at all worked in different ways, in setting out to support clients in finding jobs. Some of these efforts were directed towards improving their clients' skills, and others were about ensuring the right job was there for them.

CWLD used the traditional job coach model where a job seeker is paired with a job coach who will support them to look for work and at work. In addition they ran job clubs which gave clients an opportunity to meet up and share experiences as well as providing a venue for using technology to job search, and practise interview techniques.

> *"They all get on and they all spur each other on. Now that some of them are getting paid jobs they all want a paid job as well. And they all help each other and support each other." [Job Coach]*

Both job seeker and job coach were involved in the search together.

> *"They look on the computers, in papers and various other places but you have to look yourself as well so it's like balancing." [Participant]*

'Pure' also used the traditional job coach model, as CWLD did above. In addition they are a Project Search site. This involves working in partnership with a large employer, in this case Manchester University Hospital, and the local college.

The classroom based setting provided at Project Search allowed opportunities for job coaches to address questions around appropriate behaviour in the workplace. This included: how to dress, how to speak to your manager, personal hygiene and behaviour at work.

"At the start of the year we had a 2 week induction where we talked about what people should wear…………we had a talk about personal hygiene…….again that's something we have had a year to keep working on….we want to ensure they have those high standards because we want them to get a job." [Job Coach]

The Rose Project also worked with people in transition and although they used job coaches it was in a slightly different way to the others in that there was no one-to-one job coach work until someone had secured employment. Rose also provided a classroom setting where job seekers were working towards a qualification, an award in Edexcel WorkSkills, as well as job searching.

"*The course is teaching them the interview skills and CV writing and all the rest of it but we are getting to know the clients really well which is good when you are trying to place somebody, if you know who you are placing it makes a big difference.*" [SEA manager]

In addition to this we saw that the classroom model worked well in providing extra practical support. Our participants told us that the sense of community and belonging that the classroom and job clubs brought was important to them.
Meeting with other job seekers prevented them from feeling isolated and they drew on each other's experiences and were able to learn from each other.

"The clients take it better from each other, they feed off each other." [Job Coach]
Although not all SEAs have the resources or the time available to them, most will run a 'job club' which could take elements from the classroom approach.

miEnterprise were different again in that they used the micro enterprise model working with people who wanted to work for themselves and stay under the permitted earnings level until such time that they felt confident enough to develop their business. Although the low number of hours people worked could make some people question whether this

is supported employment, self employment was seen by those using it to be a realistic and manageable option for them. It has been recognised elsewhere as having potential.

> *Self employment can mean a closer match between individual preferences and contribution with the job, and a better fit with individual values and lifestyle preferences. As such, self employment has been viewed by some as "the next logical step" in 'supported employment. (Ridley et al, 2005: 4)*

Mienterprise gave practical support which was specific to the needs of people starting their own business, ordering stock, hiring and buying equipment, budgeting advice and book keeping. At miEnterprise there was a sense of community amongst the clients, whilst we were there people were popping in to visit and asking each other how they were getting on. There was talk of sharing their experiences and bringing together skills to strengthen businesses. For example one person made ice cream which was sold in a local cafe with strong connections to miEnterprise. There was also discussion around whether another member who ran a market stall might be able to sell her ice cream on her behalf. The staff are hoping to build on this sense of community.

> *"One of the things that we would really like to see happen is for a group of people to get together and talk about how their businesses are doing, instead of getting together to talk about what it is like to be somebody with a learning disability!"* [miEnterprise manager]

It is important that all SEAs provide a basic toolbox of practical support as outlined above. We know that people will require a variety of support and different levels of support so SEAs should tailor the practical support available to job seekers depending on their individual needs.

> *"We have a whole singing and dancing service which is the 8 o'clock calls in the morning, transport to work."* [SEA manager].

The emphasis needs to be on placing people in paid employment rather than on endless work preparation.

> *"We don't do a lot of work prep here, we believe that the best learning is on the job I can teach you till the cows come home about how to apply for a job, interview technique. Do you want to pay me for that or do you want to pay me to get a job?" [SEA manager]*

If SEAs can create an environment whereby people can job search and share experiences together, without distracting from job searching, this was beneficial for many job seekers.

4.2 Overcoming barriers: working with employers, and getting a *"foot in the door"*.

In our interviews, both job seekers and job coaches told us about the difficulties they faced trying to get into the job market and how they tried to overcome this. Participants talked about the discrimination they felt they suffered when looking for work on the open jobs market:

> *"You're disabled and therefore you can't have a job." [Participant]*

Job coaches we interviewed also spoke of difficulties in this area.

> *"I think they (employers) just don't have an understanding, I would put it down to not having any contact with people with a learning disability, or any kind of disability." [Job coach]*
> *"Well it can be frustrating trying to get an employer to take someone with a learning disability." [Job coach]*
> *"One employer said, 'sorry we don't employ people like that' and another person insisted on calling people with learning disabilities 'retards', they are some of the worst cases." [Job coach]*

As with the general population it was recognised that this is a period of high unemployment and competition for jobs is great. This period of economic downturn coupled with the other barriers was perceived as making things even more difficult.

"Jobs are like hens' teeth" [Participant]

One of the strategies SEAs used to help people get a foot in the door was to help people find voluntary work or short-term placements. Some people spoke about taking voluntary work or jobs that they were not particularly interested in as a means of getting their foot in the door.

"I'm looking for paid work at the moment but I would do some voluntary work if that was the last thing....if that was the only way I could try and get into a job then I would do that." [Participant]

"We are now looking at work trials and work experience just to get our foot in the door." [SEA manager]

"The least is about 3 hours (paid work) we try and push for but sometimes you have to go with what you are offered and sometimes it's a good way of getting in." [SEA manager]

SEAs also told us about the extensive work they did to try and persuade employers to give their clients an opportunity.

"We're doing stuff in the background, ringing companies, meeting organisations. You can ring 30 employers to get one visit." [Job coach]

Although this was time consuming it could bring positive results. One job coach told us about a sceptical employer who had been persuaded to employ someone.

Participant's story

Alan is passionate about cars and with his job coach decided he would like to find work as a valet for 8 hours a week. The job coach approached several local car showrooms. One employer said he did not need anyone but was interested in the scheme. After talking for a while he agreed to employ Alan on a Saturday. Alan needed intensive support at first as he would wander off to look at the cars and had to be brought back on task frequently. With goals and targets put in place after about six weeks he 'seemed to click into place' and was overachieving on his targets. He is now employed for two days a week as the employer has seen the advantage of being able to free up one of his other staff members to concentrate on sales.

4.3 Overcoming barriers: job matching

Some of our participants had very fixed ideas about what kind of work they wanted to do, and we referred to this as their 'tunnel'. If that particular type of job was not available, then a barrier was created for them. Three of the SEAs that used the job coach model had encountered difficulties around individuals with a tunnel.

> "*Some people have just got one thing in mind and they won't be budged no matter what you say and it's not realistic and we will say to them it's not the real world." [Job Coach]*

Whilst this could sometimes be a problem for job coaches, when job matching it often was an indication of somebody's strengths and passions which, if tapped into, could enhance their chances of getting a job that they were happy in and which would therefore be sustainable. In some cases the SEA was able to work with this and find a job that suited their interests.

However widening people's expectations was not always easy and this could become a barrier in itself. Job coaches need to strike a balance between matching jobs to people's interests and skills and being realistic with the kind of work that is available.

Participant's story

Gary is 21 years old and has a very strong 'tunnel'. When we first met, he was adamant that he only wanted to work repairing and building classic motorcycles. He is widely skilled in this area, has completed courses and holds relevant qualifications. It has been recognised by many that he is extremely talented. However it is a niche market and jobs are scarce. After initial attempts to find jobs in his chosen field were unsuccessful, the job coach attempted to get Gary to widen his job search. At first Gary strongly resisted but after gentle persuasion from job coach and his mum he began widening his job search. *"I was gently persuaded to look for other things"[participant] "yeah one of the positives with [job coach] has been that they have sort of made you think a bit wider than that"[mother of participant]* He is now actively seeking work in different areas.

Nevertheless, all the supported employment agencies talked about the importance of job matching. This might involve finding a job that matches people's interests and skills or something that fits in with their lifestyle.

"Mum and dad said 'he's not a morning person!' So I spoke to mum and dad and said what if the hours were later? And we spoke to you and said 'What if you worked later hours? Would you mind?'" [Job Coach]

Our findings reflect the findings of Banks *et al* (2010) in that people took the first job they were offered, with most being happy with that choice. Where people had not taken jobs or decided not to apply for them at all, it was because they felt the job was not suitable for them.

" She (the job coach) asked if I was interested in office work! I said no I'm not interested in office work because I wouldn't last two minutes in an office! I haven't got no office skills!" [Participant]

In one case it was suggested to a job seeker to apply for a manual outdoor job, which would involve standing for long periods of time. As the job seeker required built up footwear this was viewed by her and her family as a highly unsuitable job match.

"She can't wear wellies or anything, she's in built up shoes for mobility; out there in a field she would be falling over." [Parent]

4.4 Overcoming barriers: setting up micro-enterprises

A person's tunnel can be positively used as a basis for developing business ideas and ventures. That was an approach particularly taken at miEnterprise, who were able to be creative around working with people because they were setting up their own business in the area that interested them.

Participant's story

> Marianne is a very talented artist who has never had support to sell her work commercially. She works in a very detailed way on cityscapes, landscapes and buildings. Due to the mathematical way she approaches a subject she has decided to call her business Calculated Art. miEnterprise are now working with her on different formats and media before selling locally and online through the website. miEnterprise have arranged for a commercial scan of a couple of Marianne's pictures and she is now thinking about the prints she would like to have made and framed, as well as getting some high quality cards printed.

Recommendations

- **SEAs should share good working practice. They should work together to increase the chance of individuals getting the support that is right for them.**

- **Specialist job coaches could be employed and matched to job seekers. If a job coach has experience in a particular area, their specialist knowledge could increase the chances of someone being successful in finding the job they wish for.**

- **Organised groups are useful, where job seekers can come together and offer each other peer support to keep up their motivation.**

Chapter 5

Getting a Job

In this chapter we will look at the type of jobs people have found and some of the issues to do with applying for a job. Our participants had a wide range of jobs and hours varied from four hours a week to full time. Most of the jobs were low skilled manual work, as has been seen in other research (Bass, 2000; Ridley & Hunter, 2006 and Jahoda *et al,* 2010).

5.1 Job carving

Once an opening had been identified the job coach could meet with the employer and job seeker to discuss the requirements of both parties. Participants talked about the need to build up their hours and responsibilities over a period of time and how this helped them to adjust to the job.

Job Carving was also mentioned by three of the supported employment agencies. This can be an effective way of finding work that suits the individual and is especially useful for people furthest away from the labour market. As discussed earlier disability can in itself be a barrier as well as social barriers; however this need not preclude people from being effective workers.

> *"Most of our clients in day services would not be able to do 100% of a job that was advertised. Say they wanted to do admin, possibly our client might not be able to take phone calls, operate the switch, write messages down. So we'd meet the employer......and ask about job carving which is where you take bits out of the job and put other bits in instead so that person is 100% productive, very valued in the workplace." [SEA manager]*

Job carving was applied when placing Sean in a job in a local pub. Sean was part of a project aimed at helping people furthest from the labour market to get paid work. The story mirrors the findings of Martin (1999) that good support works well.

Participant's story

Sean has severe learning disabilities and attended a local day centre. The job coach and day centre manager met with Sean and his sister to talk about what kind of work he would like. Sean had enjoyed helping to clean at the centre and had learned various tasks. After looking at different jobs on the computer he decided he would like a cleaning job in a pub. The job coach phoned some local establishments and one agreed for Sean to have a week long work trial where he would have the opportunity to demonstrate he could manage the job. The job coach and manager talked about which tasks he would be able to do and worked out a clear routine so Sean understood what his duties were. Sean is now in paid work at the pub.

The advantage of job carving for employers was that it can free up more skilled employees from routine tasks.

'She'll put them in the baskets and distribute them in the bathrooms. So that's another job that I don't have to do. But it all needs to be done. When it's busy down here and there's only one of you it's quite hectic. The days she isn't here I do miss her.' [Work colleague]

Our Experience Box 3: People can do different parts of a job

Once the interviews started Jeff's' skills were apparent, he was a natural interviewer with a talent for putting people at ease and getting them to open up about themselves. However he did not recognise this as a skill and his self doubt in his capacity to do the job continued. Interestingly over time the co-researchers all took on different roles:

"Vicky does the transcribing and enjoys reading and writing, Jeff is brilliant at talking to people and making appointments", David takes care of lots of the technical things and presenting and Kath takes the lead on producing easy to read materials."

5.2 Overcoming barriers: the application process

"I didn't know how to do it." [Participant]

Online recruitment is now a common way for employers to recruit staff. This can be particularly difficult for people who may have trouble using technology or even limited access to it. Job clubs set up and run by SEAs can provide people with access to the internet and use of computers. The three agencies who were helping people to look for work on the open market all supported people using this medium. However they cited the problems associated with the lack of previous experience and lack of formal qualifications that people might have, which could mean application forms were often unlikely to get past the shortlisting stage. Everybody we spoke to had received some practical support in looking for a job. This included help with filling in application forms, writing CV's, interview practice, online job searching and work tasters.

The traditional interview process can be intimidating and put people under pressure. Three of the supported employment agencies we spoke to said they would rather avoid them but when this was not possible they would offer support with the agreement of the prospective employer and job seeker. Support may mean helping to prepare for interview, accompanying the applicant to the interview and supporting them during the interview. Job seekers told us that this was very helpful.

Participant: They helped me find it (the job), *and when I went to the interview he came along with me and gave me a lot of support.*

Interviewer: Did that help?

Participant: Yes it did because I was nervous, probably understandable

Job coaches were also able to offer support when candidates were unsuccessful at this stage.

An alternative to a traditional interview was a working interview or work trial where people have the chance to work for a fixed period of time without pay. This could be for a day or up to a week and gives a job seeker the opportunity to see if they enjoy the job and the employer a chance to observe their ability to do the job effectively. In one example we found Jenny had a work trial at a care home in a caring role, something she had always thought she would like to do. After the trial had finished she told her job coach that she found the position pressurising. The job coach was able to liaise with the employer and another position was found for her working in the laundry. The job was successful and Jenny has been working there for two years now.

 The Project Search used this model to give their students opportunities to try different roles with the host employer. This was highly effective. The success rate within the cohort that we visited was seven out of ten in paid jobs.

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Our experience Box 5: Working interviews

In our own experience when the original team of co-researchers were recruited we used the traditional interview approach allowing job coaches to support them in this. Eighteen months into the project when one of the co-researchers left we decided to use what we had learned from the research and hold working interviews. Candidates spent a day in the office with us and did some data analysis with the team. We found this was effective and we found out much more about their skills than we would otherwise have done

SEAs sometimes found other means of bypassing traditional recruitment processes, one SEA put on a Dragons Den type event where job seekers had an opportunity to pitch themselves to potential employers.

"The employers said this is amazing! I used the event to meet employers and one of them I've been meeting with and he wants to give one of the students a paid job. The presentations are great to showcase their skills and where they've been and what they've been doing." [SEA senior manager]

Recommendations

- **Working interviews should be used where possible, to give applicants with learning disabilities a better chance to show what they can do.**

- **SEAs need to work closely with employers. Job coaches should be trained in cold calling and promotion to raise awareness with employers.**

Chapter 6

Keeping a job

Previous work on supported employment has emphasised the importance of helping people to get *and keep* paid work. In our research we found that, not unsurprisingly, the focus of the SEAs was to help people get a job with less attention paid to sustainability of employment. The exception here was miEnterprise, perhaps because the support was mainly ongoing and the funding was designed differently. As noted by Jahoda e*t al* (2010) the psychological effect of losing a job can be considerable and attention should be paid to ensuring that jobs are sustainable. Support at work can go some way to helping people keep jobs and here we will look at where that support can come from and what form it can take.

6.1 Support from work colleagues and others

Natural support refers to support that is unpaid and is received from work colleagues, friends and family. Chadsey & Beyer (2001) found that friends at work were important. Our findings reflect those of Wistow & Schneider (2003) in that jobs did not always result in increased social networks:

> *"I've met people but I wouldn't call them friends, I call them work colleagues."* *[Participant]*

However work colleagues can play an important role in supporting people in their job which was valued by our participants.

> *"I work in the kitchen and the lady I work with she's absolutely brilliant with me. I couldn't wish for anybody better than what I've got." [Participant].*

Job coaches talked about the importance of natural support for people.

"Danny has an amazing, a really supportive manager who has adapted her diary to help him. He shares a cubicle with three other girls and they are really supportive as well............I think if that support wasn't there you would be reluctant to step back........It's very important that we work well, not only with our clients but with their team and their managers." [Job coach]

"A big part of the job coach's role is helping colleagues accept our client, it's not that they have anything against them but it's a fear of not knowing how to talk to them or do they understand or should I ask this and expect that? Just because there is somebody a little bit different they are completely thrown about how to treat them." [Job coach]

When work colleagues are not supportive it can have a profound effect on people. One of our participants left her voluntary job because she felt she was not valued by the paid staff. Another became deeply unhappy when his supervisor constantly found fault with his work and it was only when the job coach intervened that the problem was successfully addressed.

As we saw above, a sense of belonging is important to people and when work can provide this it is valuable.

"The people I work with are other people with learning disabilities, so we work as a team........so it's really, really nice." [Participant]

Project Search experience is positive in that former students who have got work within the hospital keep in touch and meet up with each other to socialise. They are also able to give peer support to a new student which gives them a sense of pride and being valued leading to increased self esteem.

As we saw in Chapter 2 the type of support given by the job seeker's family can be invaluable when seeking employment. This was also true when people were in work. Peter had experienced a successful and well managed work start which was threatened by his tendency to take drinks belonging to his colleagues from the fridge at work. The job coach was made aware of the problem and quickly did some work with Peter and

his family to impress upon him the unacceptability of this. With the help of his parents labelling his drinks and talking to him about how this behaviour might make others feel he was able to learn how to stop doing this, thus avoiding alienating himself from his colleagues.

6.2 Overcoming barriers: transport

Participant's story

Barry is a 40 year old man living in a rural area. Barry has a sensory impairment and a learning disability. He started a job in a high street store on a part time contract. Initially he was working 3 days per week but found this too much. The manager was very understanding and allowed Barry to reduce his hours until he felt able to build them back up. He also encountered problems early on when communicating with other members of the workforce. Again the manager was accommodating and agreed to disability awareness training and arranged an additional fire drill to ensure that Barry would be aware of the alarm going off. The job was very successful: *"they have been very supportive and flexible"[mother],* until there was a change of manager. Barry was suddenly expected to work late hours which was difficult in terms of transport and he also felt vulnerable about travelling late at night alone. The new manager was inflexible and told Barry's mother *"well he signed the contract."* Barry was left distraught with little choice but to leave his job.

Eleven participants mentioned transport as a barrier, eight of them being from the Cornwall site. This is most likely due to the rural nature of the area. Problems cited were a lack of transport, difficulty using public transport, and high associated costs. All SEAs provided travel training and liaised with Access to Work who are able to offer financial support to people to help with travel costs to and from work. In our own team this was used by one of the co-researchers who had to travel a long way to get to the office. How travel support was organised varied between the sites. One offered three months financial support and some travel training where it was perceived as necessary. Another

offered as routine twelve supported journeys to work which could mean accompanying the client to work, or merely ensuring that they caught a bus and meeting them at the other end. Support faded out as the client became more confident. Another provided travel training to all of their clients. The fourth provided extensive travel training when required.

> *"We get to do it ourselves, we get independent to go on buses ourselves."* [Participant]

However, despite this, transport can still remain a barrier for some. This is particularly true in rural areas and may be reflected in the general population. In some cases people relied on family support to get them to and from work, once again highlighting the value of good family support, although this is not always possible for everyone. Employers were not always understanding of the problems facing people getting to and from work. This shows the importance of job coaches being clear and realistic with employers from the start and maintaining a strong relationship so they are on hand should someone's situation change.

6.3 Understanding the different roles of the job coach

For most of our participants the role of a job coach was obvious, however a few seemed unclear about what their exact roles were:

> *"Well I don't know what or how much she does in the background……..we don't ever really talk in depth."* [Participant]

In another case a participant seemed unclear about the support she was receiving at the time:

> *"I don't know who supports me you see any more."* [Participant]

Half way through the interview process the co-researchers had to explain to her that we were not part of the supported employment agency. This indicates that there was

confusion about the role that her job coach played and what she understood about the service of supported employment she was receiving.

Most people said they got on well with their job coach and generally appreciated the support they received. The relationship between client and job coach is an important one. However people sometimes appeared to be too close or dependent on this relationship and this was something that SEAs guarded against. On the infrequent occasions when participants said they were unhappy with the support they received from a job coach, they took it personally and felt they may have done something wrong.

> "*I wondered what I had done wrong I thought I've done nothing to you I was really upset……….I just don't know what to do, I don't want to fall out with her, no I don't that's the last thing I want to do.*" [Participant]

We found that people were often reluctant to criticise the support they received for fear of offending their job coach or getting them into trouble. There was a similar feeling from parents and family.

> "*It's an awkward one to answer, we're so grateful for what they have done you know.*" [Parent]

> "*I hope I'm not going to get her into trouble or anything.*" [Participant]

Where people did criticise there was a sense that they felt let down by the job coach or their expectations had not been met. Within one SEA people's accounts about the reliability of job coaches varied. One participant claimed that his job coach "went the extra mile" and he wouldn't change anything about the support he received. However within the same SEA there were accounts that on numerous occasions job coaches had cancelled scheduled meetings at the last moment and in some cases did not turn up. One participant said that she felt "let down by this". This would suggest that the support provided within this SEA was inconsistent and that perhaps job coaches were not all offering the same quality of support.

When we asked our participants if they would change anything about the support they had received, most responded "no"; they were very happy with the support received and very grateful.

However one participant felt that his job coach could have done more.

> *"I sometimes wonder if she is putting in as much effort as she really could do, you know?" [Participant]*

One agency had a clear personal agreement at the beginning of the process between client and job coach so that people could be sure of the support they could expect. This is important because the boundaries between job coach role and social care are often blurred. They also had a clear complaints procedure in place, although this was rarely used.

One employer we spoke to talked about the danger of over supporting someone to an extent that it could isolate them from the rest of the workforce.

> *"I have to be very careful that I am not hands on with Paul very much at all. Because if I am hands on Paul will be seen as the boss's favourite, that would isolate him from the staff." [Employer]*

6.4 Fading support

Fading support is where a job coach will accompany the new employee into work to help them learn the job and fit into the workplace. Over a period of time the support will lessen until the employee is able to work on their own. The amount of support someone receives varies according to their needs. It is important that this is negotiated with both the employee and employer in order to get a satisfactory outcome. In one example an employee found the support too much and began to resent it.

> *"We try our level best to keep the same job coach, especially for the first month, sometimes we will put another job coach in after a month um sometimes that's because the client gets quite attached to the job coach and that's not always a good thing because then they won't talk to other employees" [Manager of SEA]*

On the whole our participants appreciated the support and felt it had increased their chances of a good outcome.

"It started off with the first two months she was there like every day, then afterwards as time went by she gradually just popped in and out just to see if I was OK, she didn't just like leave me here and disappear. Yeah, she definitely was a big help" [Participant]

When someone needs a lot of support at the beginning of a job this can put pressure on the job coach and can be time consuming.

"When somebody's got a job it's your priority to be there. If you need to be there every shift then you need to be there.....It's the other clients, I'd have to think at the back of my mind, oh, I've not seen them this week because I've been really busy. I really worry about that because I don't want them to think, where's she gone, she's not spoken to me this week." [Job coach]

SEAs need to be clear at the outset that this situation may arise but that when people need intensive support they will receive it. It is important that support fades where possible, not only to cultivate independence but also to encourage the employee to integrate with the rest of the workforce.

6.5 Ongoing support

Some people may always need a certain amount of support in the work place (Beyer, Shearn & Thomas, 2001). If this can be provided by natural supports then SEA's are able to concentrate their resources on new job seekers. However participants told us that it is important the SEA support remains available to people should problems arise.

"If we have a problem we just ring them up....It's quite nice to know there's somebody in the background. If things did go pear shaped we could go back and say, hey sort this out!" [Parent]

Interviewer: Do you still get support?

Participant: If I need help I just ring up and go see them

Interviewer: Has that ever happened?

Participant: It happened a couple of weeks ago. I needed to sort things out that I was supposed to get. I just rang them up and asked them to come in.

This type of support is very important when things go wrong and can ensure that jobs last. However SEAs can find it difficult to offer this as they are largely funded to get job outcomes. Once a job has lasted a certain length of time and can therefore be counted as an outcome it is not financially viable to put resources into sustaining it. Funders need to take this into account, as it is not beneficial to the employee or employer if a job breaks down.

In Stockport a monitoring team had been created to which clients were referred once they had been settled in work for a period of time and were considered stable. This meant that employment officers' workloads did not become too large to manage but ensured that support was still there should people require it. All the supported employment agencies offered ongoing support but had different systemic processes. Rose use a traffic light system, whereby everybody starts on red with intensive support in the workplace. Their need for support is reviewed at regular intervals. At amber a job coach may only offer support once a week. Green would indicate that support was no longer required. However should either the employer or employee encounter any problems at a later date Rose offered further support. CWLD could offer 6 weekly and 6 monthly reviews. As only two of the CWLD participants were in paid employment at any one time it was difficult to comment beyond noting that they each had a very different experience. One of the participants was not able to access ongoing support when she encountered problems at work following a change in management; unfortunately she felt she had no choice but to leave her job. Had the support been there and able to discuss the problem and explain the client's requirements to the new manager, perhaps this job breakdown could have been avoided. Another participant also faced the prospect of losing his job and due to highly effective and quick action from the job coach

working with the employer, the problems were dealt with and he is still happily working and considered a valuable member of his workforce. Funding restrictions can make the provision of ongoing support difficult but it is invaluable for sustainable employment. Where there is an understanding of the support available, our participants have said they valued this.

Additional support can be provided by Access to Work funding which can pay for a job coach. The use of personal budgets for employment support is starting to be used in some parts of the country. The potential here is that people will be able to tailor the support they need so it meets their individual requirements.

Recommendations

- **Long term funding needs to acknowledge the need for ongoing support.**

- **Employers should promote lift sharing schemes.**

- **People with learning disabilities in work should be able to use their free bus passes during peak times.**

- **Travel training should be available for all job seekers who require it.**

- **Job coaches should give only the amount of support required thus guarding against people becoming over reliant and dependent upon them.**

- **Clear roles should be established from the outset in order to create clear boundaries.**

Chapter 7

Moving on

7.1 Losing a job

"And then the balloon went up" [Participant]

Ten of our participants had experience of losing a job, five of them during the course of the research. Losing a job can have a significant negative effect on people (Banks *et al,* 2010). Two of our participants left their jobs because they felt under pressure.

One of our participants left her job when there was a change of management and a job coach told us of a another case when this had happened. Two of our participants lost jobs because of inappropriate behaviour.

An employer told us of a time when they had to discontinue someone's employment. He spoke about the problem this caused.

> *"The hardest bit we had was when we got somebody that personally fitted in the department but couldn't do the work and you have to say then, look I am really sorry. They were happy with us but they couldn't do what they were paid to do and that's got real emotional pull on it for management and staff. And I don't know if it's worse for the manager because then the staff don't like you very much because you got rid of somebody that they like."* [Employer]

This demonstrates the importance of ensuring a good job match for everybody.

Participant's story

Jenny worked in a large department store for several years before being made redundant. This had a very negative effect on her confidence and for a long time. She did not consider returning to work and was signed off sick by the family GP. The process of looking for work was particularly difficult for her. *"It hit her hard, there was a period in which I don't think she was interested in doing anything.....she couldn't face searching for a job in difficult times.....she couldn't stand going for the interviews at the Job Centre." [Parent]*

Participant's story

Tina had a cleaning job and had been employed for 7 months. Her co-worker was very happy with the quality of work and thought she was a 'fantastic' worker. Tina's job coach gave intensive support in the beginning to try and ensure a successful placement. This involved the use of photographs to help Tina understand the work tasks and also working alongside her colleague so she would know how to support Tina well and to develop strategies to use when she   became anxious or agitated. Tina tends to express her emotions physically and can become verbally abusive when stressed. On occasion she would raise her fist in an aggressive manner. Although her colleague was understanding and supportive the situation became too much for her in the end and Tina's job came to an end.

In the general population we would expect to see a percentage of people moving from jobs for various reasons. However given the resources that are invested in finding these jobs for people with learning disabilities, it is economically viable to spend a little more

time on doing as much as possible to sustain them. The effects of a job breakdown on a person's well-being has been researched by Banks *et al* (2010); in their study they found that when somebody lost their job they 'were left with reduced income, too much time on their hands, and feelings of failure and hopelessness' (Banks *et al* 2010: 351).

In one other case where one of our participants experienced a job breakdown due to a change in management it also had adverse effects on her physical well-being.

> *"You got so run down and so unhappy and upset we went to see the doctor."* *[Parent]*

7.2 Negative experiences

A few people reported negative feelings about work. Although some of these are shared by the general population, as Wistow and Schneider (2003) suggested, we thought some of these could be linked to anxieties associated with having a learning disability such as not being prepared for a change in plans, social exclusion and not feeling valued.

> *"It went wrong from day one. They said to him he would go in the first week for one day, and the second week two days and build up to five but he went in the first day and immediately they wanted him in the next day. Now when you say something to Alan you have to stick with what you say otherwise there's problems." [Parent]*
>
> *"I didn't like it, it was confusing. Sometimes I'd sit down for an hour, no work to do." [Participant]*
>
> *"She* (the manager) *said it's a waste of time me coming in working." [Participant]*

These experiences show the importance of good support both in the initial setting up of a job and in the ongoing support. It also demonstrates the importance of support within the workplace and how SEAs need to build relationships.

7.3 Career progression

Getting a job is only the first step in the process for people. As with the general population people we spoke to wanted to try different roles within their job or move on to different jobs. This is also true for the research team.

> **Our experience Box 6: What job next?**
>
> Our jobs are coming to an end with the end of this project. David said he would like to do more research as long as there is more travelling involved. Vicky said yes she would like to do more research and Kath said she would too and to help people to get people in to work. Everyone needs support to look for their next job, and to build on what they have achieved.

However, SEAs did not always see their role as including the task of career development:

> *"I don't think a lot of services are set up to do career development in the long term because the finances are not there. It's more about the unemployed getting into employment." [SEA manager]*

As with sustaining jobs it is very difficult for SEAs to invest resources into career progression. Sometimes they were able to find creative ways to incorporate this into their remit, for example by setting goals at review meetings and building a question into 6 and 12 month review meetings about career progression and training.

> *"So if someone had started at Morrison's and didn't want to do till training because they weren't ready we'd ask about that again at review because we want people to enjoy their role and keep the challenge. So we try and do it naturally if you like." [SEA Manager]*

Some of the parents we spoke to felt it was asking too much of the agency to go to them for support with career progression.

> *"Don't rock the boat"! [Parent]*

Not all people are interested in furthering their work development. This is mirrored in the non-disabled population. However where people want to progress, the support to give them this opportunity should be there.

Many of the people we spoke to talked about how their confidence when looking for work had increased since joining an SEA whether or not they had found work. On several occasions people said that they would be happy to try and find work themselves in the future. This suggests that the experience of being part of an SEA is itself furthering people's expectations and aspirations and self belief.

If SEAs are to be more than just a tool for getting people off the benefit system, the funding streams need to reflect the importance of personal development for the individual (Jahoda *et al* 2010). The positive effect of paid work on self esteem was reiterated when talking to the family members and job coaches of the participants who had been present throughout their journey to finding paid work. The participants themselves gave detailed accounts about the impact that having a paid job had on their lives. Participants and their families reported an increase in confidence and self-esteem once they had settled into a paid job.

> *"At first I was a bit shy and that. When you get to work I'm not shy anymore."*
> *[Participant]*
> *"It's self-esteem isn't it that you've got that job and you're being a normal*
> *productive, member of society that's got a job?" [Parent]*
> *"I'm more grown up." [Participant]*
> *"Yeah he's learnt lots of things within work but his social skills have come on so*
> *much."[Parent]*
> *"He's about 2 inches taller." [Parent]*

"And he's talking, if you watch him it's amazing! And he's interested in the person he's serving, whereas normally he looks down." [Parent]

"My son was shaking on his first day. I felt so bad leaving him ……………. Now he's travelling all over………………... Don't know where he is half the time." [Parent]

People took pride in their work.

"I had people there telling me all the time how nice it was to be served by a gentleman." [Participant]

"You actually know its valuable and how to do work. My job's kind of difficult but I get used to it." [Participant]

We will finish this report by telling you about the effect of employment on ourselves, in the research team.

> Our Experience: Box 7
>
> *"We've met loads of new people, built our confidence up"*
>
> *"Built our self esteem up"*
>
> *"I can ring people up myself now I used to have to get my mum to do it."*
>
> *"I travel on my own a lot now."*

Recommendations

- **Peer support for those in work should be provided.**

- **SEAs need to maintain a relationship with employers so they are able to support people when working conditions change.**

- **SEAs need to be available to support people through a job breakdown.**

- **Funders should take into account the need to invest in people's career development.**

- **People with learning disabilities can show how well they can contribute, by having a paid job. Their achievements should be recognised and built on.**

Appendices

Appendix 1

Literature Review

This review considers the literature that has looked at the efficacy of supported employment agencies. It will also consider literature that has looked at the value of employment for people with a learning disability as well as the barriers they encounter in finding employment. A search of the literature was conducted between August 2010 and August 2011. As this is an inclusive research project we took a creative approach to making the literature accessible to the co-researchers on the project. Articles were read by the research coordinator and research supporter, the main points and findings were written down using plain English and then pictures were added.

What is supported employment?

The Work in Progress Project is looking at supported employment agencies across the country. Supported employment agencies' function is to assist and support people with disabilities into paid employment. A major feature of supported employment is that people with learning disabilities should be paid the "going rate" for the job that they do, therefore detaching them from benefit dependency (Jahoda et al, 2008) There is a constant emphasis on the idea that people with learning disability should have access to and be supported into 'real jobs', and there has been much debate surrounding this topic. There is some tension within the field as to what comprises a 'real job'. The Association for Supported Employment (AFSE) defines a real job as one which 'would otherwise be done by a non-disabled worker' whereas others say that it is a job whereby a person is paid accordingly. Ridley et al (2005) take a different stance and argue that a 'real job' needs to be at least 16 hours or more a week in order to achieve economic and social inclusion. But this is underpinned by the rules surrounding the benefit system. Many people with learning disabilities work in part time jobs, sometimes where earnings fall under the permitted earning rate. Ridley et al (2005) surveyed over

160 services providing employment support. They found only a third of supported jobs were over 16 hours and pay rates were generally low. They argue that although *'there is nothing inherently wrong with part-time work, voluntary work and unpaid work experience, per se they are not the same as, and therefore, should not be labelled as, supported employment' (pg 2).* However to date there is no research that has looked at how people with learning disabilities define a 'real job'. The Sayce report (2011) recently stated that:

'Some disabled people opt to work part time in order to manage energy or concentration levels, treatment effects, inaccessible transport or other disability related issues. Some fulfil roles they can deliver with great flexibility to suit a fluctuating condition (for instance door to door delivery, where the work can be done at different times of the day and week as long as core outcomes are achieved' (pg 48)

Attitudes towards the part time work that many people do could be seen to mirror the experiences of women in the 1960's when there were conflicting arguments within the feminist movement as women started to move into the world of work. Early attitudes often questioned the value of job roles and the contribution their income made to households i.e. often referring to it as pin money.

History of employment and people with learning disabilities

Historically people with learning disability have been excluded from the world of paid employment, "disability equalled non-employability" (Roulstone, 2004). Things began to progress with the introduction of sheltered workshops which are employment settings provided specifically for people with a learning disability away from the open market. Although they have evidently offered earnings and an occupation to a large number of people they have been criticised because of their 'sheltered' nature and have been deemed as isolating people and providing little inclusiveness and opportunity for progression (O'Bryan et al 2000).

Some facts and figures

In recent years there has been a shift in government initiatives and it is widely accepted that paid employment in the open market is important for people with learning disabilities; 65% of this group say they would like to work (Emerson 2005) and yet only 6.4% are in work (Samuel 2010). This section summarizes information produced by the Learning Disability Coalition (Emerson and Hatton 2008) on the employment of adults with learning disabilities.

- 83% of people with learning disability of working age were unemployed
- 28% of people with mild/moderate learning disability had some form of paid employment
- 10% Of people with severe learning disability were in paid employment
- 0% of people with profound and multiple learning disabilities were in paid employment.
- Only 17% of people with mild/moderate learning disability and 4% of people with severe learning disability were reported to be earning over £100 per week.

The report notes that these figures of 17% employed are higher than reported elsewhere possibly due to the fact that the survey included people with learning disability who were not using learning disability services.

The National Audit Social Care Intelligence Service (NASCIS) provides figures on the numbers of people with learning disabilities in all forms of work, including paid and unpaid, full and part time hours. In 2009/10, 6.4% of people with learning disabilities were recorded as being in some sort of regular work, paid or unpaid. 6.1% of people with learning disabilities were in a paid job working between 1 and 30+ hours per week. The majority of people with learning disabilities in work were working part time hours of less than 30 hours a week. 2009/10 figures on unpaid work were not available. In 2008/09, 4,560 people with learning disabilities were doing unpaid voluntary work. The number of people with learning disabilities engaged in unpaid work was more than the total number of people in paid employment for the same year. There are no details on what kind of work this was.

Rates of employment differ slightly between the genders, particularly in relation to the numbers working a greater number of hours. (Lemaire & Mallik, 2008; Olson et al 2000) 1.3% of men with learning disabilities were working 30+ hours per week compared to 0.5% of women. Emerson (2005) also reported that there were more men in paid employment than women and that men worked more hours. This was across the board from people with high support needs to low support needs and even those people without a disability.

Broad, writing in Community Care in 2007 stated that

> *"Their historically low levels of employment have always represented a massive missed opportunity. A large proportion of the 1.5 million people with learning disabilities in the UK have a lot to contribute in the workplace, if only they could enter it."*

The statistics available on the rates of employment of people with learning disabilities show a significant difference between those people who want to work and those who are actually in paid employment (Emerson, 2005; Broad; 2007). However as O'Bryan (2002) noted we need to acknowledge that for some people paid work is not, and is never likely to be a realistic option.

The role of supported employment agencies

Supported employment agencies have been developed to help people with a learning disability to get into the world of paid employment on the open job market as opposed to sheltered employment. Supported employment agencies can have different ways of operating, usually they are based on the job coach model, whereby a client is offered one to one support to help them to find employment. Variations include family led jobs, when the family is at the forefront of helping an individual find and maintain employment; micro enterprises helping people into self-employment:, transition projects which work within a college:, the Project Search model when a supported employment agency works in partnership with a large employer and a college, and working within

day centres to help those considered traditionally more difficult to get into work. Supported employment will use a 'place, train maintain' approach, whereby an individual is helped to find a job and then supported to learn the job tasks. The 'maintain' factor refers to any ongoing support that may be required to help the individual keep the job. Supported employment agencies are accepted as the most valuable methods of supporting people with learning disabilities into work (Wistow & Schneider 2003, Ridley & Hunter 2006). It was estimated that in 2005, 2700 people with a learning disability had paid work as a result of supported employment (Foundation for People with Learning Disabilities, 2005)

Supported employment has been defined as:

> *'an evidence-based and personalised approach to support people with significant disabilities into real jobs, where they can fulfil their employment aspirations, and achieve social and economic inclusion' (DoH 2010)*

O'Bryan et al (2000) highlight the difficulties in accessing supported employment in the UK for people with a learning disability; there are extreme geographical variations in the quality and level of provision. A reason for these variations is the diverse way in which supported employment agencies are funded. There is commonly only short term and the target driven funding available to this sector is problematic when trying to provide consistent and high quality support.

> "Supported Employment is an emerging sector with no consistent approach to the quality of care provided" (O'Bryan et al; 2000)

Previous research has identified various successful strategies that supported employment agencies have adopted. Examples include: person centred planning where a vocational profile is created for an individual using their interests, talents and support needs to identify suitable job roles; using a career based approach where a long term view is adopted as opposed to simply getting people into the job market and quality job development for people once they have secured employment (Ridley & Hunter 2006). Ridley and Hunter (2006) argued that a UK definition of, and quality standards in, supported employment would be beneficial. Weston (2002) undertook a review of the

research literature and ongoing research and looked at the experience of people with complex needs when using supported employment agencies. They found that an individualised approach was best for this group of people focussing on user participation and choice and paying close attention to the needs of both the employee and employer. Rose et al (2005) found that high motivation in clients of supported employment agencies was a good indicator of those who were more likely to get and keep a job but that it drops off over time, they concluded that job coaches should look at ways of maintaining motivation. Wilson (2003) looked at three case studies of people who had used supported employment services. He found that creative and flexible ways of working and job carving, whereby the worker is assigned tasks that they are able to do, and swapping tasks with work colleagues where necessary, could lead to successful job placements so long as the level of support an impairment necessitated was acknowledged. He went on to argue that restructuring job roles in order to accommodate people with a learning disability and take account of their impairment meant they were able to work effectively and successfully. However this approach is in conflict with the AFSE (2000) definition of a 'real job' as one that would otherwise be done by a non-disabled worker.

Beyer et al (2008) interviewed 145 young people and their carers about their experiences around transition and employment. They argued that meaningful work experience should be available and that employment agencies should be involved in transition planning processes. O'Bryan et al (2000) stated that access to supported employment was particularly poor for young people in transition. The Foundation for People with Learning Disabilities (2005) argued that not enough is done to help young people into work.

Not only do supported employment agencies find work for people, but they will also support people once they are in work to varying degrees. Support will usually fade over time. Jahoda et al (2010) spoke to 49 users of supported employment agencies when they first entered employment and then again one year later. They found that people did not necessarily make friends at work and that if they were given tasks they were unable to do they experienced negative feelings about themselves and their disability. Jahoda

et al concluded that supported employment agencies should offer people long term ongoing support. Again as already mentioned, funding restrictions play a huge part in the amount of support able to be offered by supported employment agencies. The AFSE (2000) clearly state that:

> *"In the UK it is acknowledged that the availability of adequate and ongoing support is severely restricted by funding shortages" (cited in Wilson, 2003: 103)*

Although some supported employment agencies put time and effort into work preparation schemes, various studies (O'Bryan et al, 2000; Beyer, 2010) claim that the work place is the best place to learn a job.

Jones S., Morgan, J. *et al.* (2002) interviewed 16 people in Wales who all use supported employment agencies and looked at what makes supported employment agencies successful from the point of view of clients, employers and job coaches. Self advocates were called on as consultants to define what 'success' meant in terms of supported employment. The report concluded that doing the job well, being able to talk to the boss, training, good support from employers and providing on-going support were all important factors.

A criticism of supported employment agencies is that people are often supported into low paid and low skilled jobs. Jahoda *et al* (2010) interviewed 49 users of supported employment agencies and found that although it tended to be the more able who were supported into work it was usually into menial jobs. Wistow & Schneider (2003) spoke to 30 people with learning disabilities about their experiences of supported employment. They found that most were in low paid, low task jobs with little chance of progressing although many reported they would like to.

> *'...getting and keeping a job is not enough people with learning disabilities seek career progression as well.' (p.172)*

Career progression is not seen as a vital part of the process possibly because of the funding arrangements around supported employment agencies.

McConkey and Mezza (2001) claim that lack of motivation is a significant barrier for people with learning disability in finding paid employment. Many supported employment agencies use motivation as part of their criteria for accepting referrals (Beyer & Kilsby, 1997) A study carried out by Hensel et al, 2007 clearly indicated that people who were least happy with their situation of being unemployed were more motivated to find and keep a paid job. A more recent study (Andrews & Rose, 2010), found that there are 3 main motivators for people with a learning disability to obtain paid work.

- Monetary gain

- Social aspects

- Perceived competence

Howlin et al (2005) looked at a specialist employment service for people with autism over a period of eight years. They found this to be a successful way of supporting people with approximately 68% of clients finding employment and reporting a high level of satisfaction with the scheme. People who have been described as having challenging behaviour have also been shown to benefit from using a Supported Employment Service (Martin et al 1999). However they speculated that for some people support may always be necessary contrary to the general principle of fading support. They go on to say that funding support at work rather than elsewhere could be a more rewarding way of spending resources.

Why work is important

Research has been carried out to identify why work is important to people. The reasons most cited within the literature are financial reasons, improved physical and mental health, empowerment, giving people meaningful activity and social networking. (Forrester-Jones et al 2004, Jahoda et al 2010, Beyer et al 2010, Chadsey & Beyer 2001, Jahoda et al 2008) although Jahoda et al (2010) found that employment did not in fact lead to improved social networks. This study researched 49 participants from 24 supported employment schemes and used self-report measures to examine any changes to their participants' quality of life, mental health and social lives. They

concluded that although on the whole employment brings benefits for people with a learning disability it can sometimes make people feel worse about their abilities and lack of social status. In slight contrast to this Forrester et al (2004) conclude that although work does not guarantee social relationships it helps maintain and increase social networks and gives people the opportunity to meet people not associated with disability services.

The role of supported employment in providing a route towards gaining additional benefits such as improved skills and new network members should therefore not be underestimated (Storey & Horner 1991).

Barriers to employment

What are the barriers that cause this difference?

- Medical model

 Much of the literature identifies the main barriers for people with learning disability getting and keeping paid employment as being rooted in the impairment of the individual. Lemaire and Mallik (2008) cite many barriers to employment; not being able to concentrate, social problems, finding it hard to read and learn new things. Interestingly the solutions to these problems as suggested by Lemaire and Mallik (2008) are based within the social model of disability, (by changing things that are external to the individual), they include using natural supports, avoiding temporary jobs, addressing career progression. McConkey and Mezza (2001) identify the main barriers that prevent people with learning disability getting work as: difficulties concentrating, communication difficulties, problems understanding instruction, not being motivated, difficult behaviours, family reluctance, poor mobility, poor hand control, inflexibility and poor hygiene. Numerous research papers specify that a person's characteristics play an important part in determining the likelihood of them finding and keeping a paid job (Beyer & Kilsby, 1997; McConkey & Mezza, 2001, Rose et al 2005; Rose et al, 2010). Significantly all of these barriers fit into the medical model of disability.

- Attitudes and expectations

McConkey and Mezza (2001) reported that from their study that the expectations of support workers towards people with learning disability and paid employment were low. Support workers expressed the view that people who were able to read and write were more likely to keep a job, along with those who were deemed able to look after themselves, and those who were better at time keeping. This would suggest that support workers think that people who have low support needs are more likely to keep a job.

- Social model

In contrast to this the social model of disability identifies the main barriers to people with disabilities getting paid employment as those created by the systemic processes associated with employment. Eg, access to work and transport (Mackelprang and Clute 2009), employers' attitudes, lack of role models and the infrastructure of learning disability services, (Gosling and Cotterill 2000), information and access to supported employment and the benefit system, (O'Bryan et al 2000).

Appendix 2

Doing Inclusive Research

This project was an inclusive research project which involved the employment of four co-researchers. Inclusive research has been defined as: 'a range of research approaches that involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users' (Walmsley & Johnson, 2003; 10).
Principles of inclusive research include:

- The research question must be one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people: non disabled researchers should be on the side of people with learning disabilities.
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research.
- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities.

<div align="center">(Walmsley and Johnson, 2003, p. 64)</div>

Walmsley and Johnson (2003) state that there are two different forms of inclusive research. The first of these is participatory research where 'a sympathetic ally works alongside people with learning disabilities to do research where people with learning disabilities to do research where people with learning disabilities participate actively (Walmsley and Johnson, 2003). A more radical approach to inclusive research is emancipatory research where people with learning disabilities control the process and resources of the research and where the research process itself challenges societal barriers (Zarb, 2002; Barnes, 2003; Barton, 2005).

In this paper we outline how people with learning disabilities employed in the project became co-researchers and the ways in which we worked together as a team.   It includes a reflection by the research supporters about the degree to which the research moved towards an emancipatory approach and concludes with a reflection on the research by the co-researchers.

Becoming researchers

The first six months

The co researchers, David, Vicky, Jeff and Kath were briefed on the entire plan of the project when they first commenced employment. The co-researchers were very open in disclosing the difficulties they faced in understanding certain concepts, after all WIP is a large and complex research project. Understanding the nature of the project has been documented as being a common challenge across the board when carrying out research with people with learning disabilities, (Bigby & Frawley, 2010). We broke the project down into manageable chunks and tackled each task as it arose.

The first six months of the project were largely spent training and learning about supported employment and research. There was a big emphasis on interview techniques and a lot of practising with each other. We received research methods and interviewing training from Norah Fry Research Centre, Bristol University where people with learning disabilities had had considerable experience in carrying out research. For some of the co-researchers this was a difficult part of the research, an issue which was also reflected in Bigby & Frawley's (2010) account of working with a co researcher. Although some training was necessary to prepare the team for the project, in retrospect we could have spent a shorter time on it. Ironically much of the literature we were reading at the time was about how people learn better on the job and the need to 'place, train, maintain' rather than do endless work preparation. This was definitely apparent within our project. On reflection the co researchers *'would have rather just got on with it'*

Gathering data.

As the co-researchers had all found their jobs through a SEA they immediately had something in common with participants which they were able to build on when forming relationships. It also gave them an insight which neither the research co-ordinator or research support worker had, into the experience of being a SEA client.

.A short way into the interview process, as the co-researchers gained in confidence, they decided collectively that at times it would work better if they worked alone with support from the research co-ordinator or research supporter in carrying out interviews. The reason for this was that they felt that for some of the participants it was intimidating to be speaking to more than one person and it was often physically crowded and sometimes people spoke over each other. This was especially noticeable in one example where the participant had a hearing impediment and opted to be supported at interview by family members, and, as she lived in a small house this was a crowded environment. The decision to work one to one (with a research supporter) was a decision that co researchers took as a team and was an example of how they were beginning to 'own' and run the project.

Over a period of 12 months we got to know our participants well and the relationship the co-researchers built with them meant we were able to get some telling and rich data. The positive value of using an inclusive research approach was most apparent at this stage. The co-researchers were able to empathise with participants and share their stories so that friendships formed and participants were particularly open. This happened to a lesser degree in the other sites which we only visited twice as oppose to the numerous times we met with CWLD participants.

Interestingly over time the co researchers naturally settled into different roles, we discussed this together, the team identified for instance that:

> *"Vicky does the transcribing and enjoys reading and writing, Jeff is brilliant at talking to people and making appointments", David takes care of lots of the technical things and presenting and Kath takes the lead on producing easy to read materials."*

Data analysis

Once the data was collected we began to analyse it. This was the stage of the project that we inevitably anticipated would be most daunting in view of the amount of data we had collected. It has also been documented that the process itself of analysing data and writing up a research paper is saturated with traditional academic jargon (Chappell, 2000).

We decided to take 2 approaches to this. One member of the team had particular difficulties with reading and decided he would rather watch the films of interviews and look at what he found interesting about them and what people had said. His thoughts were recorded by one of the other team members and then typed up. The other strategy involved reflecting on the data as a group and identifying key themes.

Towards Emancipatory Research

Emancipatory research should be 'owned' by those doing it and they must be involved meaningfully from the outset (Rodgers, 1999; Barnes, 2003). We were keen to encourage the co-researchers to take ownership of the project from the beginning. This was difficult as they had not been involved in the original funding bid and they had come to the job because it was an unusually well paid position for someone with a learning disability and not because they had any great passion for supported employment. It has been argued that the way in which research projects are funded is a barrier in itself to achieving emancipatory research (Barton, 2003:323).

During the project we had many conversations about the co-researcher roles and how they compared to those of the co-ordinator and support worker and co-researchers were adamant they had no wish to 'own' the project and that it was necessary for one person to 'be the boss'.

When it came to the everyday organising of the WIP project, the research co-ordinator tended to be at the forefront. The ownership of WIP is something that we have attempted to gradually try to encourage the co-researchers to take control of. We did exercises whereby the co researchers were asked to be in control of the working day and identify tasks that need to be addressed. These have been semi successful but

ultimately the co researchers were constantly looking to the research co-ordinator or research supporter for approval and guidance. Were we merely loaning our power to the co researchers? Williams et al (2005) emphasises the need to consider carefully power and the way tasks are carried out to make sure that the non-disabled supporters are not "doing" the research. Within our inclusive research team relations within the team were such that all members of the team were able to negotiate what they did and what they did not do. We believe that this reflected a shift towards eliminating power imbalances. Although Chappell (2000) suggests that if people with a learning disability require support to carry out research, inevitably non-disabled supporters will influence how that research is carried out. We feel that this is unavoidable in this particular project, Bigby & Frawley (2010) highlight that in their experience of working with a co researcher with learning disabilities, the research supporter merely provided the framework of the work tasks needed to be carried out and guided the co researchers in doing them.

In our project when it came to decision making about the project, it was always put to the team. We discussed the lack of input that the co researchers seemed to want to put into certain decisions. When asked why this was the co researchers explained that:
"sometimes I don't want to say anything in case I get it wrong" (D)
"if I don't fully understand I don't want to make a decision"(J)
The co researchers however did emphasise that they felt comfortable suggesting ideas. There seemed to be a differentiation between being asked a direct question, which could make someone feel pressured and them suggesting an idea in their own time. Sometimes there were times when people had difficulties getting along with each other and problems with team relationships. There was regular supervision with co-researchers in an attempt to alleviate problems which was usually successful. We also discussed the responsibility of having paid work and the fact that we cannot usually choose who we work with and when. Some of the problems that we encountered in our own team were mirrored in the research stories and the positive side of this was that we were able to draw on those experiences in order to better understand what people were telling us.

However in small steps, despite the protestations of the co-researchers, they began to take control of certain aspects of the research. Firstly the decision of how to run the interviews and then later during data analysis when they worked out how best they wanted to do it and what made most sense to them. The parts of the research that didn't interest them they were happy to pass on. A sense of pride in their work and their role as researchers emerged over time.

'We're top of the class researchers!' (Kath)

Doing the research: A reflection by co-researchers

Towards the end of the project the co-researchers had a discussion amongst themselves about their experience of becoming researchers. They then wrote a short piece to record those experiences for inclusion in this report.

Beginning the research

When we started the project, David didn't expect to do so much travelling. Kath and Stuart didn't know what to expect as researchers and didn't know what it was all about. Kath found it bit scary. Kath and Vicky thought we were going to get people into work. Stuart joined us towards the end of the project and thought he would be involved in doing the interviews but they had finished.

Vicky found it hard doing the literature review Kath thought it was easier to do but David found it easy because there were easy to read summaries which were useful.

Kath found the training before doing the interviewing helped to build researcher confidence before interviewing.

Gathering the data

David, Vicky and Kath said we learnt more doing the interviews than from the training. Kath thought doing the interviews was a good way of meeting new people and understanding people's working feelings. Vicky thought the interviews were interesting and useful. David found them enjoyable to do, they were the best part of the job. Vicky thought it was useful to get to meet new people and getting to know their stories about work. David said research supporters gave a bit of guidance for doing the interviews.

Kath said it was handy to have the questions in front of you but not all of the time. David said he would prefer not to have the questions because then you can have a natural interview. Vicky said that she would prefer questions at beginning then not having them and using bullet points till she knew what to talk about but otherwise she would prefer to not have anything and just have a natural interview and a talk. Kath also said sometimes she would have questions in front of her but having a one to one chat without questions helps.

Data analysis

Vicky and Kath said they thought doing the data analysis easy but sometimes it was hard but David said he mainly found it difficult because he couldn't remember what participants said and it got David frustrated and stressed. We all said it wasn't always easy to understand the data analysis. We all agreed that the data analysis can't be made easier.

Letting other people know about the research.

We all said parents, job coaches and employers could see what we have found out. We all said the way to tell them was by using a DVD for people who can't read and who don't understand.

Reflecting on research

We all had different ideas of why people with a learning disability should get a job in research. David said they can relate to the people who they are interviewing. They got more of a motivation to get the truth out there. Kath and Vicky said it would help people with learning disabilities to have a job and for others to learn about them and the reason why they want a job and to show their employers they can do the job better than somebody who hasn't got a learning disability.

David said he would like to do more research as long as there is more travelling involved. Vicky said yes she would like to do more research and Kath said she would too and to help people to get people in to work. Vicky said the best part about being a researcher is that we get to meet new people and build her confidence up. Kath said she would like to help people to bring their confidence up and to lend a hand and give advice when they need it. David agreed with what Vicky and Kath said.

We all said that we want to do some research on different People First teams across the UK.

Our advice to people thinking about being co-researchers

- Sometimes you have to be patient and understanding as some people found it difficult to speak about their experiences.
- Prepare to speak to anybody and to travel.
- Learn about what research is.
- Be honest and open and know what you are researching about.
- A good researcher is someone who is inquisitive and has an open mind.
- Understand the job and be part of a team so you can help each other.

We all agreed working in a team with other co researchers has been BRILLIANT.

David said 'my work colleagues have helped me through the bad patches.'

By Vicky, Kath, David and Stuart

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