



Social Firms **Scotland**

Mind the Gap

**Experiences of Unemployed People with Mental Health
Problems Moving into Work**

Research Report 2003

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Forth Sector



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1. INTRODUCTION

1.1 RESEARCH STUDY

This research has been commissioned by Social Firms Scotland. The Scottish Executive funded the research as part of the Service User Development Project and the research results will feed into the ESF Community Initiative EQUAL programme, Theme A 'Facilitating Access and Return to the Labour Market', Equal Access Development Partnership.

The aim of the research was to carry out a qualitative study of the experiences of people with mental health problems, focusing on employment exclusion.

The research was carried out using focus groups of people with mental health problems drawn from the network of organisations that are involved in Social Firms Scotland. The focus groups were carried out in November and

Social Firms Scotland is a membership organisation whose purpose is to support the development of social firms throughout Scotland and to support people with a disability to gain employment. Social Firms Scotland is also part of the Social Firms UK network. For further information see www.socialfirms.org.uk.

"There are currently 2.7 million people of working age receiving incapacity benefits because of a health condition or disability ... These numbers represent a waste of talent and opportunity – both for the individuals themselves and their families, but also for society as a whole". (Pathways to work: Helping people into Employment, Department for Work and Pensions, p1)¹

The Social Firms sector in the UK had identified that the 'benefits trap' was one of the major barriers for social firms to provide services to people with severe disabilities. There was also considerable anecdotal evidence to suggest that there was a similar situation in Scotland. Research was carried out by Edinburgh Community Trust (now Forth Sector) in 1999/2000 in conjunction with Social Firms Scotland which reinforced the issues about the 'benefits trap' for people working in social firms. The research also

¹ There is a growing body of research that demonstrates that the majority of people with mental health problems are motivated to work. However, the majority of people with severe mental health problems are unemployed and the likelihood of getting back in to work is very low. The consequences of protracted unemployment on individuals are very damaging but there is also a much wider impact which is now receiving recognition.

highlighted the complexity of the Benefits System and confirmed it as being a major barrier.

Social Firms Scotland was aware of a vast number of other research studies that had been carried out in recent years. These research studies have contributed to increased understanding of the issues and improved the understanding of mental health and employment. It was identified that further targeted research into the needs of individuals with mental health problems was required in order to develop more effective responses in terms of planning, design and delivery of employment-related services.

Within both the health and social services sectors in the UK there has been the growing acknowledgement of the need to consult with and involve 'service users' in the planning, development and implementation of service delivery. Social Firms Scotland has been funded by the Scottish Executive to run a project which aims to involve people with severe mental health problems in the development of social firms which is a new response to the employment exclusion faced by this group.

As part of this process Social Firms Scotland commissioned this research to identify the specific nature of the barriers to employment faced by people with mental health problems. In order to achieve that, it was important to gain a more in-depth understanding of the complex interplay of the barriers and an insight into how individuals are affected. The focus of the research, therefore, was to find out what the issues are from the perspective of people with mental health problems.

1.2 BACKGROUND INFORMATION

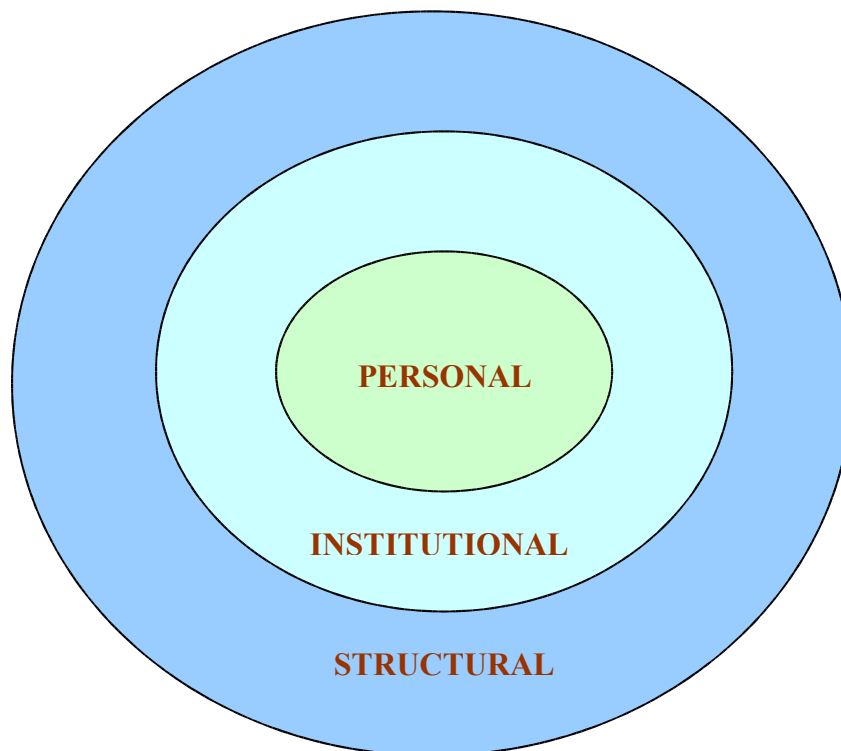
Forth Sector believes that mental health and well being can be promoted through work. Forth Sector works primarily with people with mental health problems and provides supportive employment, learning and training opportunities. The focus of activity is on developing and running social firms. Forth Sector also uses their expertise to assist other social economy organisations to develop social enterprises. For further information see www.forthsector.org.uk.

The research was conducted by Forth Sector and involved two researchers. Margaret Pressland was the main researcher and has previous experience of research having produced the 'Benefits Trap' research in 2000 and as part of a team carrying out the Action Research Project 'Working IT Out' in 2001/2002. Kevin Robbie assisted with the research. His previous experience includes a research-based MSc in Counselling which involved qualitative study methods as well as working as part of the Action Research Team above.

The research team approached the research from the perspective of trying to gain an understanding of the experiences of people with mental health problems in terms of employment. Given their previous research in this area and their work experience with Forth Sector the researchers recognised the conceptual framework that influences the research. This conceptual framework centres around the view that people experience both positive and negative influences in attempting to progress towards employment. These influences can be broken down into personal, institutional and structural.²

Table 1

Influences on Progression Towards Employment



The researchers identified that their view was that for progression to take place action was needed to address barriers in each area. Conversely, the researchers held the view that where positive influences occurred then these needed to exist in each area or progression would be hindered.³

² An example of a personal influence might be a lack of motivation, an institutional influence might be discrimination and a structural influence might be a lack of job opportunities.

³ An example of this is that an individual might be 'personally' motivated to work (positive personal influence) and the financial benefits of work might be clear (positive structural influence) but if they face repeated stigma in work (institutional barrier) then progression may not occur.

1.3 TERMINOLOGY

It is evident that the use of the term 'people with mental health problems' covers a broad constituency of interest. A brief statistical picture will be presented later. The researchers were clear that they viewed the constituent group the research was aimed at as 'people who had experienced a mental health problem and for whom this mental health problem affected their employment or employment potential in some way'.

Within this broad group of people it was recognised that it is common practice to sub-divide into two categories. The terms 'mental illness' or 'severe (and enduring) mental health problems' are used to describe those people whose mental health conditions are either long-term and/or debilitating. The term 'mental health problems' is more frequently used to include people whose mental health conditions are more moderate or of a short-term nature. The locus of the research is on people with severe mental health problems but many of the issues that emerge may be applicable for those people whose mental health problems are less severe.

1.4 OUTLINE

The research will seek to contextualise the position by summarising recent research studies and background information in relation to the employment position of people with mental health problems. This will be followed by a brief outline of the research methodology, presentation of the information gathered from the focus groups, followed by a discussion of the conclusions from the research and the recommendations made. The research study will conclude with the personal reflections of the researchers on the process.

2. BACKGROUND INFORMATION

2.1 INTRODUCTION

This section draws together information from research studies carried out in the field of mental health and employment. A summary of the main themes and recommendations of the studies is given and an outline of the common issues that have been highlighted by all the research studies.

2.2 STATISTICAL PICTURE

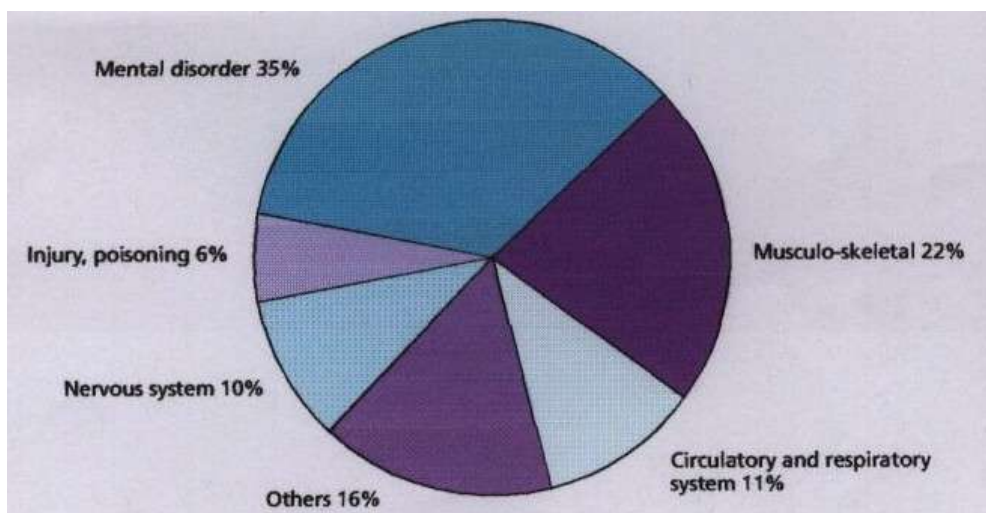
Gaining a complete statistical overview of the relationship between mental ill health and unemployment is outside the scope of this research but the following statistics⁴ present a snapshot of the scale of the problem.

2.2.1 National statistics – people with a disability receiving Incapacity Benefit

- 2.7 million people of working age receive incapacity benefits because of a health condition or disability. This is 7.5% of the working age population.⁵

Table 2

Incapacity benefits caseload by diagnosis group – May 2002⁶



⁴ Drawn from key reports and research studies.

⁵ Pathways to Work: Helping People into Employment, Summary (p1) Department for Work and Pensions, (2002).

⁶ *ibid* (p12)

Nearly two-thirds of incapacity benefits recipients receive benefits due to three main conditions:

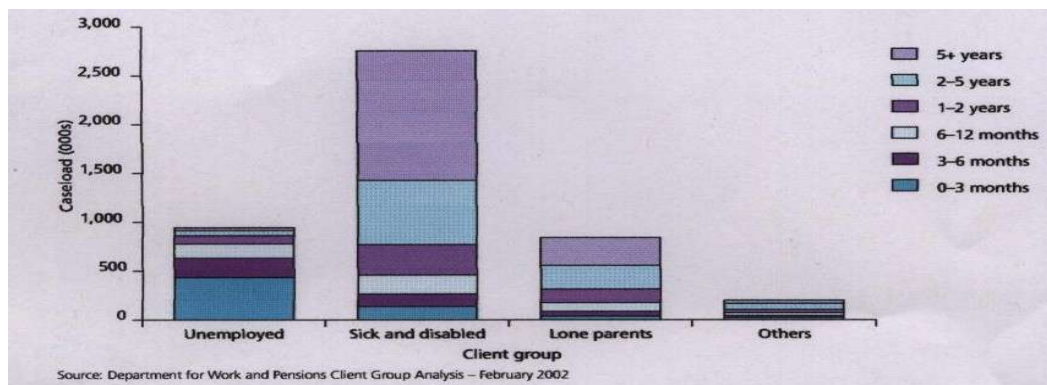
- 35% receive the benefit due to mental disorders. The majority of this group have depression, anxiety or other neuroses with only a small number having conditions such as schizophrenia or severe learning disabilities.
- A further 22% are affected by musculo-skeletal disorders.
- 11% have a disorder of the heart or a circulatory or respiratory disorder.⁷

People with mental health problems are now the largest group of people on incapacity benefits.

- It is estimated that more than three quarters of a million people claiming incapacity benefits would like to work. Even more might do so if they believed they were offered better opportunities.⁸
- Current interventions do not work. This is demonstrated by the claimant profile for Incapacity Benefit. After 6 months on Incapacity Benefit the chances of going back to work reduce dramatically. After two years on IB, a person only has a 5% chance of going back to work.⁹

Table 3

Comparison of numbers claiming key benefits in different client groups with duration of claim¹⁰



⁷ ibid (p12)

⁸ ibid (p2)

⁹ Trends in Employment for the Disabled, Department of Work and Pensions presentation, London, (2002).

¹⁰ Pathways to work: Helping People into Employment, Summary (Figure 2 p7) Department for Work and Pensions, (2002)

From the diagram it is evident that not only do the number of people on incapacity benefits outweigh other client groups but that this group also contains a significant proportion of people who have been long-term unemployed on incapacity benefits for a period over 5 years.

The recently produced Department of Work and Pensions consultation paper 'Pathways to Work: Helping people into employment' identified a series of obstacles that people on incapacity benefits face:

- The longer a person is out of work the more their physical and mental health declines.
- People perceive there are no jobs available or lack the skills and confidence to get them.
- The financial incentives to return to work can be poor.
- The transition to work can be daunting.
- There is reluctance by some employers to hire people with disabilities or older workers.
- The Benefits System still does not do enough to encourage activity.

Given the identification that the longer someone is on incapacity benefits the less likelihood there is that they will move into work, then it is possible that the longer they are on benefits the greater they will perceive the obstacles to moving back into work.

2.2.2 Research Statistics

- 1 in 4 employees will have a mental health problem in any one year. (Department of Health, 2001)
- 23% of people receiving Incapacity Benefit cited 'mental disorders'¹¹ as the reason for being in receipt of benefit (BSRN, 2001)

¹¹ The most common diagnosis included depression and anxiety with psychotic disorders only contributing to a small proportion of the total.

- 8% of the working age population (aged 16-64) say they have a mental health problem¹² that affects the amount of work they can do. **Only 17-18%** of this group¹³ of people are in any kind of employment. (Labour Force Survey, 2000)
- 26% of people with mental health problems who are economically inactive would like to work and a further 5% said they were actively seeking work¹⁴. (Labour Force Survey, 2000)

Given the scale of need identified it is worth comparison of these figures with mainstream supported employment provision for people with mental health problems.

- Of the 28,000 WORKSTEP (formerly SEP¹⁵) places on offer only 6.2% or 1,354 were for people with mental health problems. (Hayden et al 2002)

2.2.3 Statistics in Scotland – people with a disability receiving Incapacity Benefits

Findings from the New Deal Intelligence Report, Scotland, September 2002 indicate that:

- In Scotland 328,900 or 9% of the working age population were claiming an incapacity-related benefit during Autumn 2001 compared to 6.5% in Great Britain. Of this 328,900 people, 232,000 qualified to receive either Incapacity Benefit or Severe Disablement Allowance.
- Existing benefit rules presently form a serious barrier to the ability of sick and disabled claimants to take up the vocationally focused training and learning required by many to move into work, as about half of IB claimants are poorly qualified.

2.2.4 Statistics in Scotland – mental health and employment

- The 'Pathways to Work' Report drew information from a range of sources and estimated that as many as 43% of all people in Scotland who are not working may have mental health problems.¹⁶

¹² Some research studies (Durie, 2000) would argue that the stigma associated with disclosure of a mental health problem might mean that this figure is higher.

¹³ This figure is significantly lower than comparative figures for people with physical disabilities.

¹⁴ Heyman et al (2002) estimated this as a combined total of 172,000 people with mental health problems who have indicated that they are willing to work.

¹⁵ Approximately 10,000 places are offered in sheltered factories and 12,000 places in supported employment.

¹⁶ Durie, S, (2000), Pathways to Work: Towards an action agenda to create valued and sustainable employment opportunities for people with mental health problems in Scotland (p20), Scottish Development Centre for Mental

2.3 LITERATURE REVIEW

2.3.1 Background

Unemployment, economic inactivity and employee absenteeism amongst people with mental health problems is an enormous financial cost to the UK government, devolved administrations, employers and society as a whole. Additionally, economic inactivity and prolonged unemployment impacts negatively on the quality of life for people with mental illness. Anecdotal evidence has long suggested that there are both **economic and health arguments** for improving services to help people with mental health problems. Over the past decade there has been the growth of a vast body of research literature which has re-inforced these economic and health arguments as well as identifying the clear gaps in service provision.

The provision of employment-related services for people with mental health problems has been highlighted as a gap. Access to paid employment is becoming a top priority for mental health service users (Secker et al 2001, Heyman et al 2002). This demand for paid employment is not just restricted to those people with mental health problems who are close to the job market but exists among people with severe and enduring mental health problems who are currently attending day centres and training projects (Pozner & Jones 1994, Pressland 2001, Bates 1996).

Two key themes emerge from the research literature: long-term unemployment can adversely affect an individual's mental health¹⁷ (Howarth et al 1998); whilst conversely, a supportive working environment and the associated financial gain and social contact available through work can bring significant social inclusion and health benefits to users of mental health services (Secker et al 2001, McKeown et al 1992). Despite this, employment has not been seen as a health issue for people with mental health problems until recently (Durie, 2000) and there is criticism that there is still a lack of a joined up approach to provision of employment-related services for people with mental health services (Durie, 2003).

Stigma within the workplace and discrimination by employers has long been seen as the key barriers to people with mental health problems taking up employment opportunities (Read & Brooker 1996, Reid Howie 1999, Patrick 1994). This research has indicated that the fear of stigma and discrimination often prevents the vast majority of mental health service users from even applying for a job. Also, as unemployment declined and job opportunities became more readily available anecdotal evidence emerged from service users that the 'Benefits

Health. Durie estimated that the figure **may be as high as 117,000 people**.

¹⁷ This was acknowledged in the Department of Work and Pensions 'Pathways to Work' Consultation Paper, November 2002.

System' was a significant barrier for people with mental health problems taking up these employment opportunities, however, there was no real knowledge or reliable statistical evidence of the size and scale of the problem. Several research studies were carried out which have highlighted the significance of the benefits trap (Pressland 2001, Breaking the Barriers 2000).

Three major literature reviews were carried out in 2002, which have drawn out a number of the main themes and these are summarised¹⁸ later in the chapter. These Literature Reviews aim to provide a summation of the strategic development of research in the area. There have also been a number of recent research studies in the area of mental health and employment, which are summarised below along with the relevant recommendations made. It should be noted that each of these studies has specific remits and targets, and a variety of approaches have been adopted. These additional studies extend this knowledge base and increase our understanding in relation to the themes to emerge from the service users who have participated in the focus groups.

2.4 SUMMARY OF RESEARCH REPORTS AND RECOMMENDATIONS

2.4.1 Occupational Outcomes: From Evidence to Implementation – A Literature Review (A. Heyman, N. Turton, & J. Schneider) 2002

Heyman et al (2002), whose literature review was commissioned by the Department of Health, sought to take the evidence base concerning models of occupational interventions in mental health, summarise it and evaluate it with reference to the opinion of experts in the field. The focus of the activity was to identify what works, what is promising and where further evidence was needed. Heyman et al (2002) base their literature review around three main types of provision: 1. sheltered employment; 2. supported education and training; and 3. supported employment¹⁹. This conceptual framework provides the base from which research in each of these areas is evaluated. The research emerging from the mental health field is then contrasted with lessons emerging from research into provision for people with a learning difficulty.

Heyman et al (2002) note that the demand for work by service users is found in numerous studies and that meaningful occupation is one of the top ten priorities for mental health service development identified by service users. Yet, while there is a vast demand the literature review concluded, via looking at current mainstream provision, that there is an equally vast shortfall in the provision of appropriate and effective employment interventions for this group of people.

¹⁸ For those seeking to gain an in-depth understanding of the issues of employment and mental ill-health each of these three Literature Reviews should be read in its own right.

¹⁹ It is noted that the Heyman et al (2002) 'Employment Continuum' would not be readily accepted by all organisations working with disabled people and other models of 'employment continuum' have been developed.

The review firmly concluded that supported employment has the most potential to meet the occupational needs of a large proportion of mental health service users, provided it is implemented along clearly defined lines²⁰. The review also concluded that for people who cannot sustain supported employment within an 'open' setting then a range of inclusive alternative provision exists; it noted that the effectiveness of these interventions needs to be more fully evaluated in a UK context.

A vast range of key findings and recommendations were made. These related to commissioners of mental health services, managers of mental health provision, staff providing mental health care, staff providing employment support to people with mental health problems, campaigning organisations and researchers. Some of the key points that can be drawn out which relate specifically to the themes emerging from the 'Mind the Gap' research are:

- There is a need to tackle stigma and discrimination in the workplace to ensure that people with mental health problems are accepted.
- There is strong evidence of the need to convert day centre provision to provide supported employment and other employment-related activity.
- That apart from sheltered workshops almost any other kind of employment-related support to help people with mental health problems is better than none.
- There is a need for early intervention of employment-related services for people with mental health needs.
- There is a need for job retention strategies to be in place to ensure that those people who are already in employment are able to retain that employment if they become ill.
- That social firms have the potential to offer social inclusion and a route into employment for even the most disabled service users.
- That supported employment tends to be more cost effective than pre-vocational training or sheltered work.

²⁰ The report advocated an IPS approach to supported employment and acknowledged that this provision would have the best opportunity of ensuring sustainable job outcomes if people with mental health problems were placed in a job that they wanted to do.

- There is evidence of the need to have high quality benefits advice and to refer people with mental health problems to employment support specialists quickly.
- There is evidence of the need to alter the Benefits System to support transition towards employment. The Earnings Disregard was highlighted as a key barrier in terms of impeding employment potential.

As stated, the scope and scale of the literature review is large and the study deserves to be considered in isolation without the subjectivity of the researchers interpretation. The tone of the research is very positive, particularly concerning the ability of supported employment to be the main solution to the problem of employment exclusion for people with mental health problems. Heyman et al (2002) note that the current WORKSTEP provision of supported employment places (for the approximately 175,000 people with mental health problems who have indicated they are willing to work) is less than 1% of the potential demand. Given that they have identified this type of provision as the main intervention there is a vast gap between demand and supply. The challenge of the report seems to be how current service provision (day centres, vocational training and sheltered workshops) can be transformed into more socially inclusive and effective supportive employment provision.

2.4.2 Work preparation and vocational rehabilitation: A literature review (S. Riddell) 2002

Riddell (2002) sought to carry out a literature review of research into the development of vocational rehabilitation in the UK and describe the development of the Work Preparation Programme. Riddell's (2002) work is pan disability and draws on a research body from both the UK and international literature. She notes that within the research a clear difference is apparent between practice in the UK and other countries studied. Whereas in the UK individuals are often assigned to discrete programmes or services, in other countries the approach is usually case managed with individuals being directed to a range of services that meet their needs. Riddell (2002) highlights that in some countries a more radical approach is emerging with the resourcing and empowering of individuals to be able to purchase services directly from the service provider.

Riddell (2002) also highlights the debate in the literature around whom vocational rehabilitation services are for: should they be targeted at those with the best chance of finding work; or, on individuals who have never worked before and whose need is greatest. She notes that this is **ultimately a political decision** and highlights the work of Bolderson and Hvinden (1995) who identified five types of policy rationale that needed to be addressed in terms of disability and employment: market led; incentive led; integration led; choice led; or, rights led. She concludes that it is unclear whether UK policy is being driven

by social inclusion (drawing as many people as possible into the labour market) or by the notion of developing human capital (focusing on those able to find and sustain employment). Riddell (2002) believes that one aspect of this is the ongoing debate about whether responsibility for vocational rehabilitation lies within health, employment, economic development, social security, education or community care. She highlights a number of international studies that have underlined the importance of 'joined-up approaches' to disability, benefits and employment policy. The implication of this is that Riddell (2002) does not see this joined up approach in the UK and her literature research evidences the effect of a vacuum in terms of policy development at a strategic level.

Riddell (2002) acknowledges that some progress has been made from 1998 with the central thrust of the Labour government's Welfare to Work policy recognising the link between social security and employment. This has been underpinned by practical actions such as introducing effective civil rights for disabled people, attempting to remove the barriers to work, providing active help to disabled people who wish to work and the commitment to reform Incapacity Benefits. Yet she is critical of the lack of connection between welfare to work strategies and health/community care strategies. She also highlights that there is **very little evidence of policy makers engaging with disabled people and their organisations** in influencing the nature of the strategies for vocational rehabilitation and consequently the services that are developed.

As Riddell (2002) begins to look in detail at the access of disabled people to mainstream employment programmes, she concludes that there is a body of research that reveals the 'double jeopardy' that disabled claimants face: they are disadvantaged by their impairment; and in addition, often have fewer qualifications and less work experience. These factors diminish their chances of gaining employment and place them at a considerable disadvantage compared with non-disabled claimants seeking to enter the job market. Riddell (2002) recommends that one of the key questions that has to be answered is the underlying strategy towards unemployed disabled people. If equal priority is given to those with higher support needs then a larger group of people will be included in work but the services will be more expensive to deliver. Riddell (2002) seems to favour this socially inclusive approach to employment provision for disabled people and the central thrust of her argument is for greater resourcing of employment-related services for this group.

Another key recommendation is the potential to pilot 'voucher systems' that will resource and invest power in the service consumer by allowing them to purchase the services they desire. She states that this thinking is in line with the Direct Payments system being introduced for disabled people to allow them to purchase their community care needs.

Riddell (2002) identifies that there is a considerable body of research which suggests that social security systems are likely to have a major impact on the extent to which disabled people participate in the labour market. She also

identifies that there are a range of interventions (clubhouses, affirmative businesses, supported employment provision, social firms, etc) which may be able to bridge the gap between current provision and mainstream services. She acknowledges that these interventions have not been subject to robust research, concluding that most studies have been small scale. Her literature review seems to suggest that in order to answer the question 'what works best for whom in what circumstances' then piloting of these interventions is necessary and this should be framed by in-depth evaluation. She concludes by acknowledging that for this research to have validity there will need to be attempts to develop instruments that measure soft outcomes.

2.4.3 Job retention and mental health: A review of the literature (Dr. K. Thomas) 2002

Thomas (2002) carried out an extensive literature review focused on job retention. She sees this as a clear gap in current service provision, identifying that mental health disorders account for a significant proportion of both employee absenteeism and early retirement. She highlighted that people with mental health disorders now make up the highest group of people who are dependent on Incapacity Benefits and they have the highest rate of unemployment of any group of people with a disabilities. She notes that this is both surprising and alarming considering that research evidence has indicated that the majority would like to work.

Thomas (2002) also estimates that the cost of mental illness (those people with a severe mental health problem) in England is £32.1 billion (1995/6). She concludes that the research literature shows that work has a positive effect on people with mental health problems, particularly in relation to self-confidence, self-esteem, providing purpose and scheduled activity, improving both self identify and symptom management. She notes, conversely, that the literature also indicates that losing a job or lengthy periods of economic inactivity have a clear negative effect on people with mental health problems. The conclusion of her literature review is that while there have been initial steps in addressing the prevention of stress in the workplace and some action has progressed on the rehabilitation of unemployed people with mental health problems, further concentrated action is required. Thomas (2002) states that if further action in the above areas were combined with clear action in the area of job retention then there is the potential of huge cost savings to government, society, employers and individuals.

The focus of Thomas' (2002) work is clearly on job retention and she makes a wide-ranging series of recommendations. These include:

- The need to overcome the stigma of mental illness in the workplace and the community.

- Highlighting the lack of support services that specialise in job retention and return to work for people with mental illness (for both employers and employees)
- The need to build up 'natural supports' in the workplace.
- The need to provide training for employers to ensure that they create and maintain healthy workplaces for all employees
- The need for pro-activity and to develop an early intervention system in terms of return to work²¹.

2.4.4 Pathways to Work, Scottish Development Centre for Mental Health, (S. Durie) 2000

The Pathways to Work Report was the first study to take a strategic view of the area of mental health and employment in Scotland. The report was based on a comprehensive survey of literature as well as qualitative research with a wide range of people who had practical knowledge and experience in the field. This included staff and practitioners in Health and Social Services, voluntary sector organisations as well as service user groups.

The aims of the report were: to contribute to the employment of people with mental health problems in Scotland; raise the profile of employment services at a strategic level and stimulate more effective policy and practice at local level. The report aimed to be the first stage in an evolving dialogue between service users, planners and practitioners.

Mental Health and Employment is a Policy Issue – The status of mental health and employment was presented as a policy issue. Employment of people with mental health problems had been overlooked for a long time. In contrast, service users desired employment, wanted to overcome barriers to employment and get rid of the discrimination and inequalities in employment that they believed were major obstacles.

Employment is a health issue – Work was presented as a route out of poverty, leading to an economically active and healthier life. Poor mental health often reflects the social and economic inequalities of society. The link between employment and health was based on a body of research which demonstrated the positive impact work had on people with severe and enduring mental health

²¹ Thomas (2002) seems to advocate a similar approach to that carried out by GPs with patients with back injuries, where the focus is on getting people back to work quickly. She sees an advantage to ensuring that if a patient has a mental health problem while working (and they are still in work) then the focus should be to enable them to remain at work. If they are unemployed then the focus should be on getting them into appropriate work as soon as possible.

problems. Research also demonstrated the negative impact of unemployment which was associated with increased levels of anxiety, depression and neurotic disorders, decreased self-esteem, inability to concentrate and general nervousness.²²

The need to take a strategic view of Employment Services - The report highlighted a lack of strategic guidance in policy and planning at national and local levels. It also highlighted the lack of service user involvement in planning the delivery of services.

The size and scale of the problem – A major problem identified in the report was the lack of published information and statistical analysis of the employment status of people with mental health problems in Scotland. The report drew on a number of sources to estimate the size and scale of the problem with a view to identifying the demand for employment services. The Pathways to Work Report drew together statistics from a range of sources and estimated that as many as **43% of all people in Scotland who are not working may have mental health problems.**²³

Identified major Barriers to Employment – The report outlined the major external barriers faced by people with mental health problems gaining employment. These were:

- the lack of flexibility in the Benefits System
- the lack of supportive work opportunities
- stress at work
- the prejudicial attitudes of employers and society in general

The need to develop a Strategic Framework for Service Delivery – The report highlighted the need for a large number of agencies and organisations across sectors to work together to develop a strategic and co-ordinated approach for delivery of effective employment services that meets the needs of service users.

2.4.5 Barriers to Accessing Employment, Education and Training, The New Futures Fund Initiative, 2000

The New Futures Fund Initiative (NFFI) was set up in May 1998 by Scottish Enterprise in response to the need for an element of employment-related provision for the most socially excluded individuals to enable them to progress

²² Warr, P, (1983), Work, Jobs and Unemployment, Bulletin of British Psychological Society (p36, 305-311).

²³ Durie, S, (2000), Pathways to Work: Towards an action agenda to create valued and sustainable employment opportunities for people with mental health problems in Scotland (p20), Scottish Development Centre for Mental Health.

along the path to education, training and employment. The NFFI addresses the needs of clients by encouraging agencies working with individuals to develop and target provision appropriate to their situation in relation to the labour market.

The Summary Paper was produced in September 2000 and is written within the context of the NFFI and also within the wider context of current research and policy development in the field of social inclusion. The research included a range of excluded groups including people with mental health problems.

Difficulties in collecting statistical information - The report comments on the difficulty of collecting statistical evidence for some excluded groups and attributes this partly to the nature of some of the groups being researched. It was noted that the lack of accurate statistical evidence of numbers of people who are excluded could hamper the development of workable responses.

Low level of economic activity of people with mental health problems - The report estimated the overall proportion of people with a disability of working age at between 19 and 21%. People with mental health difficulties account for 8% of that group and they have the **lowest economic activity** rate of all disabled people with only 21% of people with mental illness participating in the labour market. These statistics were based on the Labour Force Survey – Labour Market Trends July 2000.

Barriers to employment – People with mental health problems face specific barriers to employment. These included:

- Stigma/discrimination – There is a lack of understanding within society of mental health issues. In employment the disclosure process needs to be examined. Specific examples had been reported in the study where employers had sacked clients when they had disclosed their illness. The impact was that service users feel pressurised as to whether or not they should disclose their illness.
- Misconception – There is often a misconception that people with a mental illness have learning difficulties.
- Inflexibility of the Benefits System – Specific points made were that the Disabled Persons Tax Credit only works well for service users who live in rented accommodation. The Benefits System does not take account of the nature of mental health and the possibility of regression. Moreover, the stress of having to deal with the Benefits System can often make this client group even more ill.

The report recommended that considerably more support should be made available for service users when they were being introduced to potential employers and support also provided for employers throughout the same process.

A further priority was the need to influence recruitment practices and policies of employers.

A key issue for service provision was the significance of timing and appropriateness of interventions with clients to avoid drop-out and mismatch of opportunities.

2.4.6 Breaking the Barriers, (G. Keetch) 2000

The report was based on a research project into employment barriers faced by people with disabilities in the UK. A survey of people with a disability who wanted to enter or return to work was carried out. The term disability within the survey covered the range of disabilities such as people with physical disabilities, learning disabilities and enduring mental ill health.

The research project was funded through ESF Horizon programme and taken forward by a partnership which had developed through the London and South East Horizon Network. The group came to recognise, through the course of their work with clients, that people with a disability faced a number of barriers when trying to return to employment. Issues included: benefits; housing; and the attitudes of employers.

The research project presented quantitative and qualitative analysis using a large-scale postal questionnaire and case studies. The individual case studies demonstrated the key flaws and barriers within the Benefits System and provision for people with disabilities. They also highlighted the major hurdles experienced by individuals.

Making the transition from welfare to work – The report highlighted the need for recognition that paid and unpaid work, training and studying are all valid forms of progression from welfare to work.

People with mental health problems had the highest rate of unemployment – The Report also specifically noted in its findings and recommendations that **people with mental health problems have the highest rate of unemployment of any group of disabled people.**

Inflexibility of the Benefits System – The central problem identified in the report was that the Benefits System does not allow for partial and fluctuating conditions. Also, financial difficulties associated with the Benefits System can lead to a worsening health condition and can create further disincentive to return to work.

The report “reinforced the need for government to listen and make significant changes to the current Benefits System to allow people to take the very real risk of leaving welfare and entering employment”.²⁴ A number of suggested changes to the Benefits System itself were made with a view to making it more flexible and less restrictive.

A major element in the report’s recommendations was the need for people with a disability to have time to adjust to a working environment. Also that their disability may mean they move into and out of employment at intervals.

2.4.7 The ‘Benefits Trap’, (M. Pressland) 2001

Forth Sector carried out research within Scotland into the scale and nature of the benefits trap for people seeking to move into employment. It was funded through the ESF Employment Community Initiative (Horizon Strand) and the National Lottery Charities Board and carried out in conjunction with Social Firms Scotland.

The social firms sector in the UK had identified that the ‘benefits trap’ was one of the major barriers to the employment of people with severe disabilities. There was considerable anecdotal evidence of the existence of the ‘benefits trap’, however, at that time no work had been done to quantify the extent of the problem in Scotland.

A questionnaire was sent to organisations providing employment or training services to people with a disability within the social firms sector in Scotland, leading to a sample of 2025 people engaged in activity within 31 organisations. This was followed up by more in depth, comprehensive research within the social firms sector and the collection and presentation of individual case studies. The final report highlighted the complexity of the Benefits System and reinforced the issues about the ‘benefit trap’ that people with a disability faced. The main findings were:

- 75% of those paid £15.00 or less due to the earnings disregard rules would work more hours if it had no effect on their benefit
- 59% wanted to work in paid employment

²⁴ Keetch, G, (2000), [Breaking the Barriers: A report of the research project into employability barriers faced by people with disabilities in the UK \(p49\)](#), Dacorum Borough Council

- There was a clear preference for part-time work (40.6%) but a significant number wanted to work full-time (18.4%)
- 45% saw the benefits trap as the main reason for not working
- 57% saw the benefits trap as the main reason for not working additional hours
- The main concern expressed was losing benefit entitlement if paid employment did not work out²⁵

The key recommendation of the report was the development of a transitional employment scheme that provides the flexibility required for people with a disability and disadvantage in the labour market to be able to move towards employment. The report highlighted that this lack of transition effectively trapped people with a disability into unemployment, the stigma of 'incapacity', social exclusion and poverty.

2.4.8 Challenging barriers to employment, training and education for mental health service users: the service users perspective. (J. Secker, B. Grove, P. Seebohm) 2001.

This research was commissioned by a network of statutory and voluntary organisations who were part of the Care Programme to Work (CPTW) network in Sheffield. The commissioning bodies had the aim of using the results of the survey to inform future service development.

Secker et al (2001) carried out a survey of mental health service users engaged with the CPTW project. The aim of the survey was to discover the needs of service users in relation to employment, education and training. The study methodology utilised service users as the interviewers and the survey involved 156 face-to-face interviews and 12 focus groups (involving 133 people).

The survey looked at a wide range of areas of vocational need and the key results to emerge were:

- 90% of the participants stated they were interested in work. Secker et al (2001) acknowledged that this was a very high level and was indicative of the fact that those who were surveyed were involved in an employment-related programme.

The above statistic has attracted a degree of criticism as being unrepresentative. While the headline figure is accepted as being

²⁵ The other concerns expressed were stigma in the workplace, lack of clear benefits advice, lack of skills and lack of ability to build up stamina to work.

unrepresentative of the wider population of people with mental health problems at large it does raise an interesting dichotomy in terms of the other results. If this group are representative of those (potentially 172,000) people with mental health problems who want to work but who are unable to access employment then perhaps the results show the crucial barriers that need to be tackled to assist this group to make the transition to work.

- 37% of the group had a long-term goal of paid employment and 25% wanted full-time work.
- The most significant barriers to return to work were: employer attitudes 83%; mental health²⁶ 80%; the Benefits System 69%; lack of work experience 54%; lack of appropriate support 53%; and lack of skills/qualifications 51%.
- 43% wanted 'work experience' in open employment as a stepping-stone to work and 40% wanted 'work experience' in a shelter/supportive work setting.
- The key phrases used by service users when describing what they wanted (whether that was for education, training or work) were: "flexibility"; "choice"; "support along the pathway".

The research also highlighted a number of issues:

- The Benefits System presents a major barrier to employment by denying service users the opportunity to move through a step-by-step approach to paid work. This barrier is due to both the inherent financial penalties within and the inflexibility of the system.
- There was a sense that benefits advice was not 'trustworthy' and unless there was easily accessible benefits advice from people that service users trusted then this was a serious barrier to them participating in employment-related activity.
- That service users viewed social isolation and joblessness as important issues that needed to be tackled together.
- That discrimination and stigma present a major barrier to the employment aspirations of mental health service users.

²⁶ This includes factors such as concentration, fluctuating motivation, fear of relapse, etc.

The survey concluded with a vast range of recommendations. In terms of assisting service users to make the transition towards employment, the potential solutions that were identified were social firms, supportive work experience in open employment and supportive voluntary work.

2.4.9 Barriers to Employment (L. McCormack) 2001

The Report was commissioned by Scottish Enterprise Glasgow following the work of the Employment Zone (Workless Households) Project. Benefits issues were found to affect other excluded groups and the report was expanded to cover a range of excluded groups. There was not a specific focus on mental health. However, the research included a focus group with a group of people with a range of disabilities which raised a number of relevant issues.

The study focused on looking at unemployment benefits and transition to paid employment.

Motivation to work – Half of the members of the focus group were not thinking about taking up employment because they thought it would be impossible to support themselves and their families. However, people were motivated to work. Indeed, of all the excluded groups interviewed in the research, this group was the **most** motivated in respect of wanting to find a job. Money was only a part of the motivation to work. People viewed employment in the way that it could transform every part of their lives.

Benefits Issue – a number of issues were raised specifically about the Benefit System as a barrier. These included:

- the inflexibility of the Benefits System.
- lack of information and misinformation from advice sources about the impact of part-time and full-time working on benefits.
- lack of understanding about disability within the Benefits Agency and the Employment Service.
- the complexity of interaction between various employment and/or disability 'benefits', Housing Benefit and Council Tax Benefit and the lack of advice and support surrounding this interaction.

In general terms, the combination of these factors created **a fear that taking up employment could result in loss of benefits** with potentially devastating effects on the individual and perhaps the whole family.

The report stated that "it would act as an incredible incentive to disabled people if they could work but **still receive some benefits**".²⁷

2.4.10 Working IT Out, an action research project, (L. Arnott, C. Scott, M. Pressland, K. Robbie) 2002

The Beattie Committee Report "Implementing Inclusiveness Realising Potential" commented on the needs of young people with mental health problems and highlighted that they faced major barriers in gaining access to employment. The Beattie Report recommended future actions to improve the employability of young people and identified the potential of social firms to support the transition of young people into work.

The Working IT Out action research project was funded by the Edinburgh Youth Social Inclusion Partnership (EYSIP) and was carried out by Forth Sector. The aim of the research was to find out how relevant and appropriate the social firm model would be for engaging young people with mental health problems in employment. It was based on Action Research, which was carried out with the involvement of a group of young people with mental health problems over a 6 month period.

The research identified that young people with mental health problems suffer disproportionately from exclusion. The barriers they experience in accessing employment were identified as: lack of educational qualifications; managing medication and symptoms; stigma; sustaining the working day; and the Benefits System. Again, the lack of flexibility and the complexity of the Benefits System were highlighted as significant barriers.

As far as working in a social firm was concerned the young people involved in the Action Research project welcomed the supportive working environment of the model. However, they saw the social firm very much as a 'stepping stone' rather than an end in itself. This contrasted with Forth Sector's experience of working with an older client group (25+) where the aspiration for the majority was for longer term 'alternative employment' within a supportive environment. The young people involved in the research were ultimately interested in obtaining employment in the open job market.

²⁷ McCormick, L, (2001), Barriers to employment (p34), Economic Inclusion Team, Scottish Enterprise Glasgow.

2.5 COMMON THEMES

There are a number of common themes within the research studies and it is important to draw these together to provide an up-to-date picture of research in the area.

2.5.1 Discrimination and stigma

Discrimination and stigma associated with mental health within employment and the wider society was highlighted in all of the research studies. Durie (2000) drew on research which provided evidence of discrimination. In a research study carried out in Fife most companies were found to be employing low numbers of disabled people and even lower numbers of people with mental health problems. There was found to be a variation of understanding among employers about the abilities of people with mental health problems and they made decisions on the basis of their own perceptions of mental ill health.²⁸

2.5.2 Gaps in Service Provision

Although there are a range of service providers and service provision, the research base indicates that there are clear gaps in provision. Mainstream Job Centre Plus provision is focused on brokering employment for those close to the job market and health/social services provision is focused on assisting people who have high support needs to be maintained in the community. Between these two service areas exists a large gap for those people with mental health problems who want meaningful occupation but who are 'not job ready'. A number of innovative approaches have emerged, particularly within the voluntary sector, in terms of bridging this gap but service provision is not complete and the models have not been rigorously evaluated. There are indications that the Welfare Benefits System actively works against some of this innovative service provision and contributes to the lack of transition towards paid employment for this group of people with a mental health problem.

2.5.3 Lack of Supported Employment Provision

Given the scale of the employment exclusion faced by people with mental health problems and the indicative motivation of a significant proportion of this group of people to work, there is a clear lack of supported employment provision.

²⁸ Fife Employment Access Trust : Mental Health and Employment, unpublished, Reid Howie Associates (1999)

2.5.4 Policy Vacuum

A number of the research studies have indicated that, ultimately, the decision over whether to end employment exclusion for people with severe mental health problems is a political one. These studies have highlighted the policy vacuum that exists in terms of addressing this significant social exclusion issue. This strategic vacuum is exemplified by the lack of a joined-up approach to addressing the barriers to employment faced by people with mental health problems.

2.5.5 The need for improved advice about welfare benefits and employment

The lack of comprehensive benefits advice was also a common theme. McCormick's (2001) study in particular identified a lack of information about benefits for people in the disability focus group and commented that "all of the people in the group would have benefited from receiving all relevant information relating to full-time and part-time employment in order to allow them to make an informed decision".²⁹

2.5.6 Raising awareness of mental health

All of the research studies highlighted the need to raise awareness of mental health with employers and with statutory agencies such as the Benefits Agency and the Employment Service (now Job Centre Plus).

2.5.7 The Benefits System

The Benefits System has been highlighted as a major barrier to people with a disability in taking up employment in all of the studies. This included the complexity of the system, anxiety and stress experienced in claiming benefit and the rigidity of rules which prevented people trying out work because of the fear of losing benefit. The interaction of these issues created a 'benefits trap' for many people.³⁰

2.5.8 The lack of flexibility in the Benefits System

The situation was raised in all of the research studies. It was well summarised by Durie (2000) who commented that the majority of people consulted in the research identified the current lack of flexibility as being a major barrier to people with mental health problems obtaining employment.

²⁹ McCormick, L, (2001), *Barriers to employment*, Economic Inclusion Team, Scottish Enterprise Glasgow

³⁰ *ibid* (p39-41)

2.5.9 Specific changes required to the Benefits System

The need for specific changes to the Benefits System rules was highlighted by the studies which had looked in more depth at the Benefits System as a barrier to employment. The recommended changes were targeted at the most restrictive and inflexible of the Benefits Rules. The changes were seen as a major priority to allow people the flexibility that was needed for a gradual transition from welfare benefits to employment.

- To allow for flexibility in approach and fluctuating health - to allow a person to move in or out of employment without penalty.
- To raise the level of the earnings disregard from the present rate to a more realistic figure.
- To address the issue of the 16 hour restriction on working hours.
- To address the issue of subsidising the costs of supported accommodation to make work a viable option.
- To introduce a transitional employment phase between 'incapacity' and 'capacity' which will allow people with a disability to build up work skills, confidence and stamina.

2.6 CONCLUSIONS

Mental health and employment has been a neglected area for many years. Until recently there was little information about the size and scale of the problem. This has implications for the quality and effectiveness of employment support services and for the type of services that are needed by service users.

There has been a recent growth of a body of research into the area of mental health and employment. These research studies have helped to give an understanding of some of the major issues. This body of research demonstrates that a sizeable proportion of people with mental health problems who are economically inactive are motivated to work. However, people with mental health problems form a very diverse group and within that motivation to work lies a wide range of individual needs.

To address this there is a need to develop a more strategic approach to policy, planning and delivery of employment services which would involve a large number of agencies and organisations across sectors working together.

Although there appears to be some consultation with service users groups it was noted that there was a lack of service user involvement in planning the delivery of services. Also, much of the evidence about the specific barriers to employment is still anecdotal and more research about the needs of service users is required.

There are difficulties in collecting statistical evidence about the employment status of people with mental health problems in Scotland. This lack of reliable information has considerable implications for developing policy, developing co-ordinated responses to the problems and providing effective employment services.

It is evident from the research that alongside stigma and discrimination there is a growing body of evidence to support the belief that the Benefits System is a significant barrier to employment for people with severe mental health problems.

3. RESEARCH METHODOLOGY

The research study was a qualitative approach.

3.1 ADVISORY GROUP

The researchers drew together an advisory group to assist in the research design. This advisory group was a mixture of professionals working in the mental health sector and service users of mental health services.

The advisory group actively contributed to the research design through a series of telephone conferences prior to, and following the pilot focus group.

The advisory group agreed that the research activity should consist of an unstructured interview using prompts³¹ to create the environment for setting the scene. The advisory group also identified that a pilot was necessary to test the research design.

One of the other discussions within the Advisory Group was the geographical spread and number of groups. The major constraint on this was the time allocated for the research and the budget to carry out groups. The decision was to run 3 groups in different geographical areas.

3.2 PILOT FOCUS GROUP

The researchers were concerned that the focus group format may prove uncomfortable for some of the participants. To alleviate this concern the advisory group suggested running the focus groups within 'familiar' environments for the participants.

The researchers were also conscious of the need to create a relaxed environment for the participants and to develop rapport. To assist this the researchers ensured that the rooms were comfortable and that refreshments were provided. The researchers also provided space and time at the start of the process to allow participants to express concerns or raise issues.

³¹ The prompts were a series of picture boards with images related to employment and several sections of a video 'Working Like Crazy' where people with mental health problems discuss their experience of working in 'user-run businesses' in Canada. One of the service users on the advisory group had seen the video before and felt it would provide a useful and non-threatening introduction to the topic which would stimulate discussion. The advisory group viewed the tape to select segments.

The 'pilot focus group' was run in conjunction with the Studio 11 Art & Design Project (a Forth Sector project). The project workers promoted the research to their group of students. The pilot took place at Forth Sector's office in October 2002.

The pilot commenced with an outline of the purpose of the research, a discussion of confidentiality and an explanation of the process. Following this, 2 segments of the 'Working Like Crazy' video were shown. The initial question asked was "what did people think of the video?" and this provided the platform for discussion. The 'visual' prompts were referred to throughout the discussion. One of the researchers acted as facilitator of the discussion by asking questions related to the issues raised. The other researcher recorded the information on a 'visual' chart with a series of diagrams and notes and at the end of the process facilitated a discussion of the details on the chart seeking verification of the information.

At the end of the 'pilot' the participants were asked to review the process. The only suggestions for alteration were to reduce the amount of time viewing the video and that the other 'visual' prompts were unnecessary.

Following discussion with the advisory group both these suggestions were incorporated into the research.

3.3 FOCUS GROUPS

Three focus groups took place. The venues were arranged by the host organisations who promoted the focus groups to their clients and the clients of partner organisations. The administration of the focus groups (dates, information, expenses, paperwork etc) was shared by the host organisation and one of the researchers.

The focus groups took place in Aberdeen, Glasgow and Edinburgh.

The process was:

- Introduction of researchers and participants
- Explanation of purpose of research
- Discussion of ground rules regarding confidentiality, space, use of mobile phones etc
- Viewing of video
- Initial question framed around response to video

- Unstructured facilitated discussion with recording on chart that was visible to all participants
- Review of diagrams and details on chart as part of process of internal verification
- Completion of paperwork

The focus groups were facilitated by the researchers. Discussions were tape recorded and transcribed by a member of Forth Sector staff.

Participants were not remunerated for participating in the groups but were offered travelling expenses.

3.4 SELECTION

The advisory group suggested that in order to engage participants the focus groups should be held within familiar environments. It was decided to run the focus groups in conjunction with members of the Social Firms Scotland network who would promote the focus groups and encourage participation.

The participants self selected on the basis of information provided.

The focus groups were hosted by Momentum (formerly Rehab Scotland) in Aberdeen, Flourish House in Glasgow and Intowork in Edinburgh and many of the participants have had contact with these organisations. Some of the participants came to the focus groups from out with these organisations having been encouraged to do so by other support organisations.

3.5 ETHICAL ISSUES

With all qualitative research, ethical issues surrounding participation arise. The primary consideration of the research team was to ensure that the confidentiality of the participants was maintained.

The research team explained the purpose of the research and advised that participants had the right to withdraw from the process at any point and any information given would not be utilised if they withdrew.

In addition, the work with the advisory group sought to ensure that there was service user involvement in the research design. This led to the suggestion that information should be recorded on a chart ('visual' format), which would

allow internal verification of the process. The additional purpose behind this was to create 'ownership' of the research by the participants and the advisory group felt strongly that this was a vital component of the research.

The main ethical consideration was the obligation to those people who agreed to take part. Research involving human subjects depends on the willing co-operation of participants. Consent was expressly indicated through turning up, yet it is recognised that it is impossible to obtain truly informed consent for what is a process in action. Participants volunteered and were advised that there was no compulsion on them to take part. This was safeguarded by explicit outlining of the right to withdraw from the research at any point, in the knowledge that any data collected would be destroyed.

The researchers were of the opinion that there was an obligation to deal honestly with the participants, minimise intrusion into their lives and protect them from any harmful consequences. One clear implication of this was that the people approached were not to be misled about the purpose of the research in order to encourage participation. The researchers ensured that the descriptions of the research and its objectives were factual and correct.

3.6 ANALYSIS

3.6.1 Method of data analysis

The method chosen was qualitative research based on a grounded theory approach. This approach aims to inductively develop themes from a systematic analysis of the data based on phenomenological sensitivity, rather than formulating a hypothesis in advance, which is then tested against the data that is collected. The advantage of this approach is that it seeks to challenge assumptions and look beyond the literature to arrive at new theoretical formulations.

By using a grounded theory approach it was recognized that a multi-faceted complex picture would emerge where there would be a requirement to sift and select the relevant data. Yet it is also recognized that the data collection and analysis can never be value free or totally objective and will always be open to inner subjectivity, which is built on implicit or explicit assumptions.³² Although the aim was to bracket off or suspend these assumptions, where it has been recognized that this was not possible these assumptions are detailed.

³² The main assumption related to the personal, institutional and structural influences that affect progression towards employment.

3.6.2 Framework for analysis

It was apparent that organising and treating the material produced from the interview notes was going to be a highly labour intensive activity.

The framework developed for analysing the data was driven by the information given by the participants. It allowed for the methodical treatment of all similar units of analysis. There were 4 key stages to the analytical framework that were used:

- Familiarisation
- Developing a framework
- Indexing and categorising
- Mapping and interpreting

3.6.3 Familiarisation

Before beginning the process of coding the data the researchers had to become familiar with the range and diversity of the material. This stage allowed them to gain an overview of the body of material. This process involved repeatedly reading the interview notes.

This stage allows the material to be treated as a whole, rather than fragmented. The aim was to retain the actual experience of the participants in the focus groups. As the researchers carried out this activity they started to list the key ideas and recurrent themes. The aim was to give the researchers a general atmosphere of the material and allow the analysis to be guided by an inductive process in order to combat their recognised preconceptions. As discussed, it is evident that the process is inherently subjective but the repetition aims to allow for more objectivity. During this process the researchers began to form hunches about the key issues and emergent themes. Once the researchers had started mapping the data they were able to return to these initial hunches and issues to retain an objective anchor.

3.6.4 Developing a framework

The next stage involved returning to the researchers' original notes and attempting to develop a framework for the themes and issues that were emerging. The aim of this stage of the process was to create the framework which would allow for a fuller sifting of the material.

3.6.5 Indexing and categorising

Following this stage the material was indexed which allowed easier retrieval and exploration. The index references were recorded on the margins of each interview note with a letter/numerical system, which linked back to the factors that influenced the style of the framework.

Each passage had to be examined and the meaning agreed. This was done on the basis of how it stood on its own as well as within the context of the interview as a whole. One of the key difficulties is that a passage, and even single sentences, can contain a number of different themes, each of which had to be referenced. The advantage of this multiple indexing is that it helps to identify patterns of association and can confirm or contradict some of the hunches upon which the original framework was developed.

Following this, the indexed units were grouped into clusters. Each unit was placed into as many clusters as seemed appropriate. The clustering helped the researchers to see other patterns and the contexts in which they arose. When the clusters had been developed each was allocated a category and then placed in relationship with each other. This led to the construction of a framework with main categories and sub-categories.

3.6.6 Mapping and interpreting

When the process of indexing and categorising was complete the next stage was to start to map and interpret the data as a whole. The aim then was to search for structure in the evidence and then to search for any explanations.

The main area of analytical work was trying to find associations or patterns that had emerged from the material. Questions such as, 'Were there certain characteristics or approaches that were emerging across the range of responses?' arose. These associations could be derived from explicit statements by the participants or from implicit connections.

Following this, the researchers began to look for explanations. These explanations were initially geared around the questions that had triggered the research. They also increasingly sought to address the questions that arose from the return to the literature review. At this point the researchers were moving back and forward seeking to link themes, issues and patterns with previous research material. This allowed them to view whether new themes or issues had emerged from the research itself. This activity was carried out primarily by M Pressland and then verified by K Robbie. Where decisions had

to be made then these rested on the views of M Pressland who was more immersed in the material.

3.7 SUMMARY

Having outlined the research methodology, the analysis of the data is presented in Chapter 4 and the researchers' personal reflections on the research process are contained within Chapter 5.

4. PRESENTATION OF DATA

4.1 INTRODUCTION

The data from the focus groups will be presented around a series of direct quotations from the participants followed by an interpretation of the issues that the participants identified as crucial to them in terms of their experience of employment and mental health problems.

The research also included a small number of interviews with managers and staff working in the mental health sector. The purpose of these interviews was to present the themes emerging from the research and to measure the extent to which recognition of the themes existed. These interviews act as an external verification of the themes but the core presentation of data centres on the experience of the participants who have experienced mental health problems.

4.2 PARTICIPANTS OF FOCUS GROUPS

Twenty people with mental health problems participated in the focus groups. Anonymity has been assured to participants. Profiles of participants are attached in Appendix 1.

The group profile of participants is outlined below:

- The age range of participants was early 30's to late 50's
- 11 women and 9 men participated.
- 16 of the participants were unemployed. Two people had been unemployed for less than 1 year and 2 people between 1 – 3 years. The remainder of participants (12) had been unemployed for over 3 years and 6 of these people had been unemployed for 10 years or more.
- 1 person was employed in a social firm, 1 person employed part-time in open employment, 1 person was a student and 1 person was self employed.³³
- 17 participants were in receipt of state benefits.

³³ The self employed person was still in receipt of benefits.

- The majority of participants were engaged in some form of 'supportive' employment-related activity, including part-time employment in social firms, voluntary work or training.

4.3 THEMES

A range of themes and issues were discussed within the focus groups. The major themes were:

1. Employment, including health issues and stigma
2. Personal experiences of employment
3. Motivation to work
4. Barriers to employment
5. The Benefits System
6. Employment support needs

A range of different experiences and views were expressed in the focus groups and this added to the depth of discussion. However, there was a consensus within each of the focus groups that the six main themes above were the main issues affecting participants. There was also a convergence of views across the focus groups.

4.4 EMPLOYMENT

4.4.1 Employment is a Health Issue

"I've been ill for 10 years ... you think you are going to be well but then you get ill again and it's a huge upheaval in your life".

"When I was in hospital I was dismissed by my employer ... when I came out I had no job and no money and I had to wait 8 weeks for benefits to come through."

"It's about losing control of your own life and that's the scary thing about relapse, it's the loss of control."

"Before I got ill and lost my job I could afford to go to the theatre and watch a show – it gave me something to aim for."

Participants described the situation they find themselves in when they fall ill. It has a devastating affect on the whole of their lives - family, jobs, and financial situation. The general view of participants was that there was little progress with their mental health in the hospital system and that once they became ill it was very difficult to regain control and regain the life they had.

There was a view that the impact or 'upheaval' of becoming ill is so damaging that people try to keep going and try to ignore it rather than risk the consequences of going into hospital and starting the downward spiral.

The participants saw a decline in their mental health as being linked with unemployment. Becoming mentally ill starts a chain of events that leads to unemployment, poverty and continuing ill health. It is significant to note that all of the participants had a work history but a significant group had been unemployed for over 10 years, during which they had remained as patients of the health service or reliant on social services.

Participants stressed the need for early intervention and support at the first signs of illness, whether that was at hospital or in the workplace. Early intervention could make a huge difference and could help people to regain control of their lives before they become caught in the perpetuating trap of social care and ill health.

4.4.2 Stigma

"Once you have got the 'tag' of mental health problems you are stuck with it."

"As soon as you say you have got mental health problems you can see the shutters come down."

"People are scared of it. It is not like a physical condition that you can see. It's difficult to form relationships and friendships."

"If the rest of the staff get to know you have a problem they tend to treat you differently. Some people are scared."

"There are two hospitals in Aberdeen ... when you go into Forrester Hill, beside every bed there's a bottle of lucozade, a bunch of grapes and a bunch of flowers. When you go into one for psychiatric conditions there's nothing like that."

"It's difficult to socialise after work when you are on medication because you can't drink. People ask why and you tell them. The feeling you get back is, you're not one of us."

"I do voluntary work in the community. It shows I am still capable of going into that same world I fell out of ... I can just be accepted again for a while."

The stigma of mental health affects people in all aspects of their lives - socially, in the community and in employment.

Stigma in the wider context

Participants felt that they were treated differently because of the stigma associated with mental health. For example, many said that friends and workmates do not come to cheer them up with the usual "bunch of grapes" when they were in hospital with a psychiatric condition. Participants had also experienced stigma from their neighbours and, in general, from the wider community and they had tried to make sure that nobody found out that they had mental health problems. There was a wide range of 'institutions' that the participants identified as being sources of stigma, examples given ranged from the Post Office, GP surgeries through to community centres. Each focus group spent a significant proportion of time dedicated to a discussion of the effect of stigma in terms of reinforcing social isolation. The cause of stigma

was often identified as a lack of awareness and understanding of mental ill health.

Stigma and employment

Some people saw stigma as only one barrier to employment while others saw it as the main barrier to employment.

Participants perceived that employers assume that all people with mental health problems are unreliable. Because reliability is such an important feature that employers look for in their staff, participants were unable to see how they could overcome that particular obstacle.

Participants believed that they had been actively discriminated against in recruitment. They were convinced that if an employer became aware of an individual's history of mental health there was absolutely no possibility of ever being considered for the job even if they had the same qualifications and experience as other candidates, or indeed, if there were no other candidates at all.

There was a dilemma about the disclosure of their history of mental health in job applications. Participants were at a loss to know how to deal with the issue because they were unable to find trustworthy guidance or advice. They were also concerned that the information they gave at the application stage would not be kept in confidence and may be passed on to other employees.

There was a strong need for acceptance at work, particularly from colleagues and workmates and to be treated the same as everyone else. Participants explained that one of the worst aspects of becoming mentally ill were the attitudes of the people that they had worked with.

Some of the participants who had trained or worked in social firms identified the lack of stigma within social firms as one of the crucial aspects of the supportive working environment. These participants saw the persistence of stigma within other employment opportunities as a major factor in their decision to remain within the supported working environment.

4.5 PERSONAL EXPERIENCES IN THE WORKPLACE

"When you have mental health problems and you get too much pressure at work you start to fall ill again."

"The employer puts people under pressure. They want people to work the maximum amount of overtime."

"Where I worked I was forced to do overtime. I wasn't allowed to leave my work station. So I was missing lunch breaks and things like that."

"I had to give up my job. Because they knew I was a good worker they were always giving me overtime. There was just too much pressure and I became ill."

"I ended up having three different jobs at one time – I was in charge of display work, I was a sales person, I was doing promotional work and had to deal with lots of other things as well."

"When I went back to work I was actually bullied ... if people know you're vulnerable they can home in on you."

"You get people that pick on you ... I've had that so many times."

"I couldn't go back to my job because the problems came from the job. The manager wasn't taking responsibility for his job. More and more responsibility was being put on me. The situation didn't get any better ...I'd been in the job for six years."

Participants had considerable experience of employment and the workplace. With several exceptions, participants had been in employment at some time before becoming mentally ill, some of them for many years.

4.5.1 Stress in the Workplace

Participants gave many examples of stress and problems they had experienced in the workplace. The main stress caused in the workplace was due to pressure created by the following circumstances:

- Some employers kept adding work to already heavy workloads.

- Stress was caused by job boundaries that were unclear and a lack of guidance or support.
- There were many examples given of people being forced to work overtime.
- Some participants had been given too much responsibility and just left to get on with it.
- There were many instances of employers not providing support for people at work including employers not listening to or dealing with issues and problems when they arose. There were also examples given of managers actually blocking complaints going to higher levels of management to avoid taking any action.
- There was a lack of support from any source. There were instances where colleagues or workmates who may have given support felt unable to do so because of fear of retribution from their supervisor or manager.
- Bullying and being picked on by colleagues because of a person's mental health were also prevalent and a major cause of stress.
- Complaints were usually made verbally to the immediate supervisor or manager so it was difficult to make a formal complaint to a higher level of management, Trades Union or other source of assistance.

Where participants had become ill when in employment they expressed strongly that they could not have returned to the same job because the factors that had caused their illness would not have changed, they could not expect support from their employer and they feared the stigma and discrimination from other employees.

Some participants had positive experiences of work and there was general recognition that some companies have a more positive attitude to mental health and do provide support. Where participants had positive experiences they were able to identify benefits such as: working with people, helping to build the business and the feeling of contributing at work the same as everyone else.

One of the participants had started her current job on a temporary basis and had successfully applied for a permanent job. She really enjoyed the job and had experienced no problems with other members of staff.

One of the participants had worked with a company which had been very flexible and accommodated his need to sometimes 'walk off the job' and take a break. None of his colleagues had commented or made an issue of it.

4.6 MOTIVATION TO WORK

"Money has to be one of the prime considerations but ... with me it was just sitting in the house watching daytime TV climbing the walls."

"There is a certain status that comes with having a job".

"I wanted to get out of the house. Where was my day going? Bed. Sleeping."

"It keeps your mind off your own problems and gives you more to think about."

".. I felt that I had to get back to work because if I didn't, I didn't know what I was going to do because I was so isolated."

4.6.1 Reasons for Wanting to Work

The participants who were involved in the research were motivated to work and gave a wide range of reasons why they thought it was important. The reasons for wanting to work varied among individuals.

Although money was important it was, by no means, the only motivating factor. Other motivating factors included the status that comes with a job and work, the need for routine and a structure for the day, the need to relieve isolation and the need to keep active and not dwell on problems.

Participants also highlighted that there are social and financial pressures which could lead to people going back to work when they were not ready or fit for work. For example, some participants felt there was stigma in the community about not working. Also, there can be a build up of financial pressures after being ill for a period.

4.6.2 Part-time Working

Although participants were motivated to work they did not necessarily want to work full-time in the open market. A small number of participants were considering the possibility of taking up full-time employment in the open market. The majority, however, had a number of concerns and misgivings about employment and were considering supported employment options.

Participants had a preference for part-time work and saw it as a 'stepping stone' that could lead to full-time work. Others wanted to work part-time because they were concerned about their capacity in terms of stamina and strength to sustain a full-time job. A further consideration was that some people are unable to work in the earlier part of the day because of the effects of their illness and/or medication.

4.6.3 Supportive Work

"It's given me a lot of confidence, gives me a routine to the day, helps me focus. I am still in and out of hospital but I would have had to stay in a lot longer if it wasn't for the work I do."

"I have an interest in what I do but there's more to it. It's working with people who have been ill and understand what you are going through."

"Getting up at a certain time, meeting people and just feeling better at the end of the day that you've participated in some sort of work."

"I have worked for a year or so and had a varied experience so I know what I can and can't do."

Participants were very positive about the value of employment-related activity and experienced a range of benefits that were a mix of social and work goals.

Participants described their experience of long-term unemployment and ill health. The effects were very undermining and both physically and psychologically people had become completely unaccustomed to having any kind of structured, routine day-time activities. Participants described how their 'body clocks' would have to adjust to the structure of the working day. This would take a period of time. Participants had genuine concerns that they could 'sleep in' initially when starting a new job and give the wrong impression to the employer. The 'early morning' start is particularly difficult for people who are taking certain types of medication.

Feelings of isolation, low self esteem and confidence made it very difficult for them to re-engage with work and the prospect of having to meet new people. Indeed, some of the participants expressed the difficulty they had in even "leaving the house", let alone go in to work.

The benefits of employment-related activity had made a huge difference to the lives of the participants who had taken it up. Participants described how they had developed an interest in the work itself and now had a reason for getting out of the house and meeting people. The routine also helped them begin to adjust to having a structured day. The environment was supportive and they were building confidence through working with people who understood their needs. There was a recognised value in what they were doing and the feeling of participating in the work of the organisation.

An important aspect of employment-related activity was the opportunity to try things out. Many of the participants expressed the need to “start again” and not to go back to the type of work they done before. In a lot of cases it had been their job that had contributed to their mental health problems. Employment-related activity provided an opportunity to develop new skills and test out abilities in a supportive environment.

One of the major concerns about employment and mental health was the likelihood of a relapse. Fluctuating health and a cycle of having to go back into hospital is a syndrome that some of the participants live with. However, being engaged in interesting work provides a positive focus and a purpose in life that lies outside of the illness. Although it may not be possible to escape the cyclical nature of the illness, some participants clearly identified that the benefits they gained from meaningful work markedly shortened the stay in hospital and their involvement with health-related services.

4.7 SPECIFIC BARRIERS TO EMPLOYMENT

“You go for a job where you don’t get paid for a month, you’ve got costs – you can’t go to work – it’s just not possible.”

“From what I can gather ... if you take a job ... you’re only going to be maybe £10 to £20 better off – it’s not making much of a difference and financially it's not on.”

“If you go to work for an employer that doesn’t know the symptoms, that’s daunting.”

“I just find it so difficult knowing whether I’m fit to go back to work or not – and so do the professionals.”

“It’s not what they say to you, it’s what they don’t say. You walk into the office and it goes quiet – and you know they have been talking about you.”

“Becoming ill again could happen any time, that’s why I have not tried to get a job.”

In addition to the Benefits System, participants described what they perceived as specific barriers they faced to employment. These barriers were related to financial considerations, the effects of illness and fear of relapse.

4.7.1 Financial Considerations

Participants highlighted some very practical financial difficulties in seeking work. Additional costs include travel to the Job Centre and to interviews, lunches and buying suitable clothing to wear for interviews. They did not know of any additional financial allowances or incentives to cover these additional costs and people did not have sufficient money to cover the cost themselves.

Actually being in work also incurs additional costs which are similar to those described above. However, there is the additional barrier of the monthly pay system and the necessity of having to wait 4 weeks for payment. The majority of participants found that this would be impossible for them and their families.

“Is it worth it?” “Am I going to be better or worse off if I take up a job?” These were the questions participants asked themselves. Comparisons are also made between current benefits and income from employment. The strong perception was that participants would only be marginally better off and, could possibly be worse off, particularly as the type of work usually available would be low paid.

The decision to take up employment is not purely economic. Participants had experienced major difficulties in obtaining the correct level of benefits for their particular circumstances and it had taken considerable time, energy and stress to do so. Therefore, if the job did not work out the thought of having to go through the stress of applying for benefits all over again was very off putting. There were also significant fears that if the job did not work out there was no guarantee of returning to the same level of benefit as before.

4.7.2 Health Issues

The effect of medication was a major issue for some of the participants. One of the side effects was drowsiness which could interfere with a person’s ability to get up early for work. There are other side effects that could interfere with performance at work. Participants felt that employers did not understand the symptoms of mental health problems or the issues about medication.

4.7.3 Fear of Relapse

Some participants experienced fluctuating mental health and expressed great concerns about the very real possibility of falling ill again whilst in work. This fear had prevented some participants from seeking work altogether. Others had attempted to stay in the job market, which had meant having lots of different short-term jobs over a period of time.

This was a complex issue for people to deal with. Several participants had experienced the situation of becoming ill at work and not recognising the symptoms. The change in their behaviour had become noticeable to other members of staff. This was when participants had experienced some of the worst discrimination and stigma. As it came from work colleagues it was felt more deeply and had been particularly damaging.

4.8 THE BENEFITS SYSTEM

Participants expressed a great deal of frustration and dismay about the Benefits System. The main themes raised by participants are outlined below. However, it is important to note that many of the issues are inter-related.

- Entitlement issues and lack of advice.
- Complexities of the Benefits System.
- Employment and the Benefits System including Permitted Work Rules and issues about full-time and part-time working.
- The need for flexibility

4.8.1 Entitlement Issues and Lack of Advice

"When I became ill and first registered I didn't have a clue about benefits."

"I found out what benefits I should be on by accident."

"There is no certainty that you are entitled to any benefit or, if it is decided you are, that it will be backdated."

"There are lots of different benefits and if you don't know what they are you don't know if you are entitled."

"You are left to try and work it out for yourself."

Participants expressed their frustration at the lack of advice about benefits on becoming ill. This lack of support had a major impact on people who were struggling to come to terms with a whole set of threatening new circumstances which had arisen because of mental health problems. The lack of advice and support was endemic and prevalent within the range of institutions: the hospital system; social care; Benefits Agency; Job Centre Plus; and supported employment agencies. The complexity of the Benefits System and the lack of understanding of the system, even by those administering it, was a significant factor in this frustration and perceived lack of support.

"It took 6 to 8 weeks for the money to come through. I would not have survived without friends and relatives to help out."

"My payment was delayed for two months. I got into debt, became more stressed and anxious and my health just went downhill."

"I was ill and lost my job offshore and had no idea about benefits and was living from my savings."

All of the participants had experienced problems and delays in registering for and receiving benefits. This was a major cause of financial hardship and stress. Participants believed strongly that there should be early intervention and a benefits 'safety net' for people to avoid some of the personal and financial hardship. This should come into place when people first become ill with mental health problems.

4.8.2 Complexities of the Benefits System

"You get these huge forms to fill out that are like a book and you think 'oh my God, it's a nightmare'."

"You find yourself out of a job after 20 years and think you will get advice on your situation that will take account of all the factors... but that doesn't happen ... it's all hearsay from relations and friends and you can't rely on that."

"You would have to be a Philadelphia lawyer to work out all the combinations and permutations."

"It took me months to find out what my situation is."

"It's taken me a year to get my situation sorted out."

Having become ill participants had struggled to find their way into the Benefits System. Once in the system they were very fearful of changing their current status because of the danger of falling out of it again. The complexities of the Benefits System and lack of credible advice was a barrier that all of the participants had to deal with. The uncertainty of the situation caused stress and anxiety.

"When you go through the hospital system you get a social worker to help you but I wasn't part of any system and got no help."

"I got told to apply for Incapacity Benefit by one adviser and DLA by another and every time I tried to sort out the problem at the Benefits office I got agitated and things got worse and worse."

"The staff at the Benefits Agency don't help ... they don't understand mental health problems."

"Social security offices have had a lot of hassle from people and they had to put up the glass barriers ... so they're not friendly."

Participants were looking for specialist advice from advisers that they could trust who have the technical knowledge of the Benefits System, the ability to understand the nature of mental health problems, take the whole range of an individual's circumstances into account and provide authoritative and credible advice.

The perception of the participants was that this support was not available from the Benefits Agency. The result of this was a reinforcement of inertia due to a fear that if circumstances changed people might be worse off. The participants identified that they often looked to Benefits or Employment 'Intermediaries' (CAB, Supported Employment Agencies, etc) to provide advice and support but were aware that the complexity of the Benefits System meant that this advice was not always reliable.

4.8.3 Employment and the Benefits System

"I am hoping to go back to work soon but my big worry is that if I don't get some benefits I'll have to go straight back to work full-time and I am not ready for that."

"It's hard enough for people who are well looking for jobs but if you are having to worry about benefits as well it makes it much more difficult."

"At least they are coming to recognise that you still need benefit and the income from work and that the two can go together."

"£66 per week was 'pie in the sky' for me because I was on other benefits."

"Why £66 a week and why only 16 hours work?"

"I'm in supported accommodation and realistically could not earn enough but I would like to see some sort of compromise."

"It's shocking being limited to the amount of work you can do. I am offered overtime and I can't do it because I would be breaking the rules."

"£20 a week is discouraging and there's no incentive to work more than 5 hours a week."

"I got diagnosed with a mental health problem in 1994 and then I went back to work. Five years later I ended up in hospital again."

Participants were concerned about what they perceived as a major leap from being unemployed and in receipt of benefits to full-time employment. Some of the participants were considering taking up employment because there had been some improvement with their health. They wanted to start with part-time work initially because they were unsure about their capacity to sustain a full-time job. However, they were unsure about what the impact on their benefits would be and they were very reluctant to re-enter the eligibility 'lottery' and go through the stress of applying for benefits all over again.

Participants acknowledged the value of Permitted Work and hoped that there would be further developments towards the concept of allowing people to work, earn income and to retain some of their benefit entitlement. However, participants found that the way the new Permitted Work Rules worked was confusing and difficult to understand. They also found the 16-hour limit on working hours very restrictive. Some of the participants were looking for a stepping-stone into full-time work and the 16-hour rule prevented them from building up the hours they needed to help develop their stamina.

The £20 earnings disregard was seen as very restrictive and unfair. If people worked more than 5 hours a week the organisation they worked for would be in breach of the Minimum Wage legislation. However, participants thought 5 hours work in a week was far too low to enable them to develop their working capacity to the stage where they could progress into the employment market.

Some of the participants were engaged in employment-related activity on training schemes but said they found this confusing as they were uncertain how to progress. Some had support workers, others did not. Some had tried out transitional employment schemes but found the time limits a barrier.

People who lived in supported accommodation were in a particularly difficult position. It would be necessary for them to earn a very high salary to offset the cost of supported accommodation.

Participants expressed a strong view that due to the fluctuating nature of mental health problems there was a real possibility of becoming ill again. This was perceived as a major barrier to taking up employment and coming off benefits. Participants were aware that it was now possible to regain benefits at the same level within a specific period if the job was not sustained but they had no confidence that it would happen in practice and feared what would happen if the relapse occurred after the 'specific period'. Their concern was that they would be worse off.

4.8.4 The Need for Flexibility

"I think the crucial word is flexibility. When I go into a job and I am well I get a lot done and then there's a gradual coming down when I start getting ill – so there should be a safety net project ... and then build up and be able to come back."

"It's tailoring the job and tailoring the timescale. I have periods when I'm brilliant and other times I've got failings."

"I would need a steady rise back into employment to avoid another breakdown."

"A good thing about working part-time is that if you can work it with someone else you could work a job-share to suit both of your needs."

"For me flexibility means that I could work more hours when I felt well but I would not be pressurised to work overtime."

There was general agreement among participants that the lack of flexibility in the Benefits System was one of biggest barriers they faced. Most of the participants on benefits were engaged in some form of activity including part-time permitted work, supported training or voluntary work. However, they were not able to develop any further towards employment because of the rigid rules and restrictions within the Benefits System.

Participants emphasised that within any group of people with mental health problems there was a great diversity of experience and needs. Some people may be able to make the transition to employment in a relatively short time whereas others may never make that transition. However, there is very little opportunity for individuals to test the water and find out what the appropriate level is for their needs and circumstances.

4.9 EMPLOYMENT SUPPORT NEEDS

Participants described a wide range of different support needs in relation to employment. These are outlined below in the following areas:

- Individual needs for support
- Type of support services required
- Experiences of support
- Employment in Social Firms
- Support needs in open employment.

4.9.1 Individual Needs for Support

"I have been in and out of hospital ... so I have the revolving door syndrome. But I'd have been in the hospital a lot longer if it wasn't for the support project I go to."

"As soon as I told her I had mental health problems she said I don't think this training course is for you. We've had people like you before who couldn't last the pressure."

"I was ill and couldn't hold down my job and was under pressure from the mortgage company ... I was put in the direction of disability support and that is where it all went wrong for me ... I got the wrong advice, the wrong placements ... things got so bad I had a complete breakdown, lost my house and was homeless for a while."

Individual needs of people with mental health problems cover all aspects of a person's life: health; family; employment; finances; and debt. There is an inter-relationship of factors which create a very complex situation for advisers and service providers. However, it is important that people receive the right type of advice and support at the right time. The impact of bad or wrong advice can have very serious consequences for the individual. One of the participants described how after receiving the 'wrong advice and support' he ended up with a worse health condition, had a complete breakdown and ended up homeless.

Participants also highlighted that intervention at the right time can have a very positive impact and reduce time spent in hospital. Ideally, this should be early intervention from advisers who have professional knowledge and experience of the area of mental health and employment.

4.9.2 Type of Support Services Required

The variety of needs described by participants appears to be typical of what could be expected from such a discussion group. Other research noted that "in any randomly picked group of service users there will be people who have never worked and people who have held responsible jobs. There will be a wide range of occupational interests and a wide variation in how people think their mental health problem will impact on their capacity to work".³⁴

³⁴ Durie, S (2003) Mental health and employment policy for Scotland, Scottish Development Centre for Mental Health.

This, of course, has significant implications for the design and delivery of services for people with mental health problems.

Participants described the key elements they thought should be included within service provision. These can be categorised into: 'personal development'; 'advice'; 'education and training'; 'employment-related activity'; and 'employment support'.

Category	Key Elements
Personal Development	<ul style="list-style-type: none"> • Reinforce motivation • Build confidence • Develop learning in the broader sense • Develop into work goals
Advice	<ul style="list-style-type: none"> • Specialist benefits advice including <ul style="list-style-type: none"> ⌞ Entitlement to benefits ⌞ Work benefits compared with non-work benefits ⌞ Hands on help to fill in benefits forms ⌞ Advocacy to intercede with Benefits Agency • Debt and debt management • Advice about further education • Advice on the range of options available including supported employment, voluntary work, permitted work, open employment and social firms.
Education and Training	<ul style="list-style-type: none"> • Accredited qualifications
Employment-related Activity ³⁵	<ul style="list-style-type: none"> • Work experience • Vocational training • Work-based training • Developing core work skills • Voluntary work • Job search skills

³⁵ Where people can take the first steps into employment.

Employment Support	<ul style="list-style-type: none"> • Quality supported employment which helps people to develop routine and structured work activities in a supportive environment. • Develop coping skills • Job coaching • Development of 'core skills' within a realistic work environment • Transitional support • Vocational training
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Participants commented on the difficulty of obtaining comprehensive advice and support that was relevant to their health and employment needs. They stressed the need for knowledgeable and reliable advice. This ideally should be provided by a single source or facility as a package that is tailored to the needs and circumstances of the individual.

The lack of advice in this area was highlighted in a recent paper³⁶ which found that the chances of finding a service that will help an individual into employment are dependent on where they live, what diagnosis they have (if any), who their GP is, what links their Community Mental Health Team has established with local networks and what information can be sourced in the local community.

The participants highlighted that it was difficult to progress due to the lack of coherent service delivery covering all the areas outlined. The researchers noted that service provision within each of the focus group areas was patchy with participants reporting access to some of the core components and a complete lack of service provision in other areas. The effect of this was to reinforce inertia on the part of the participants and to solidify the sense of being trapped in a 'revolving door' of some services.

Another issue that emerged in each of the focus groups was the time-limited nature of service provision. The participants frequently commented on the feeling of being processed through a service. This type of comment was linked with barriers to progression, a fear of relapse if pushed too early and the lack of an appropriate service to move on to. The participants commented on the frustration this created.

4.9.3 Experiences of Support

³⁶ Durie, S. (2003) *Mental Health and Employment Policy for Scotland*, Scottish Development Centre for Mental Health.

"Some of the centres you attend you are just forgotten about but the one I go to now actually channel you and the idea is to help you get into work."

"I think there are supported places but there are no guarantees of a job."

"You learn the different trades but when you come to get a job in the real world there doesn't seem to be enough employers who are sympathetic to mental illness."

Many of the participants were attending various centres, projects and support agencies for training, voluntary work, advice and guidance. Participants felt that they had benefited a great deal from the support of these organisations and that this had an impact on the rest of their lives.³⁷

However, some problems had been experienced in the area of employment. Several participants commented that they had experienced a lack of understanding about mental health from staff of some of the employment support agencies. One of the participants had experienced particular difficulties with a supported placement. The placement had failed because the job was completely unsuitable. His health had suffered drastically as a result and he felt badly let down both by the placement provider who had misjudged the situation and the employer who had no understanding of the needs of people with mental health problems.

There were other concerns about supported employment. Participants expressed concern about whether there were sufficient organisations providing supported employment and whether the type of employment offered was suitable in terms of the support needs people had. The participants often linked issues about requiring supportive work with concerns about stigma within open employment.

Several of the participants had been involved in 'Transitional Employment Placement Schemes'³⁸ and had the perception that, despite the development of skills during the placement and the support received, there was little prospect of a job at the end due to other barriers. Participants commented that a better service would be provided if stronger links were established between supported employment providers and employers.

As well as identifying gaps in the service provision to assist them to move towards employment, the participants also felt there was a gap in terms of

³⁷ The participants had a very broad understanding of the concept of 'supported employment' and were not focused on that provided by the Workstep Programme.

³⁸ Run via clubhouses

job retention. It was commented that there were very few services to help people retain their jobs when they fell ill. This lack of support was identified as one of the factors behind a number of participants losing their jobs.

4.9.4 Employment in Social Firms

Social Firms

A **social firm** is a business that provides employment opportunities for people who have a disability and are disadvantaged in the labour market. Social firms have both commercial and social objectives. They operate in the market place generating income through sales of goods or services and they also employ a significant number of employees who have a disability and are fully integrated as staff within the business.

"It's a stepping stone, like feeling the temperature of the water to see if you can actually manage a full-time job."

"One of the benefits of a social firm is getting a wage packet like everybody else."

"You could get a permanent job ... it's stability and security and everybody needs that."

"You start on therapeutic earnings but some people go on and get part-time jobs and full-time jobs. Some people are now supervisors and managers."

"It helps to be able to work with people who remember you are unwell."

"We are setting up a social firm but there's going to be just as much stress as anywhere else."

"The one big difference is you can have bad days but the job's still there for you."

"One of the important aspects of a social firm for me is the chance of progression to the job market."

Participants found many positive aspects of working within a social firm. Many of the views expressed were related to the flexibility and the range of opportunities that social firms offered which include:

- 'testing the water' and trying out work in a supportive environment.
- adjusting to a work routine and developing stamina.
- the sense of having a real job with real pay.
- progressing to jobs within the social firm.
- progressing to open employment, if desired.

It was recognised by the researchers that the specific focus on social firms grew out of the context or content for the participants. It should be noted that the issue of support via social firms emerged from the participants without direct questioning on the issue. The sense was that the participants were motivated to take up employment and that they saw the best employment options as having the following key characteristics:

- Secure and supportive environment
- Working with people who understand mental health problems
- Work without stigma in an inclusive environment
- Feel valued
- Test stamina for real work
- Flexibility and opportunities to work part-time
- Real pay
- Opportunity to progress to open employment
- Possibility of permanent job in the social firm

Although not restricted to social firms, these are core components of good practice within the social firms that exist in the UK. It is also significant to note that within both the UK and Europe, social firms are primarily established to provide support for people with mental health problems.³⁹

Some of the participants either worked or trained with a social firm and others were involved in projects to develop them. All of this group have visited existing social firms. The participants saw the supportive working environment within a social firm as providing one of the services they required to progress. The participants who wanted to work within social firms were divided on one key issue: was a social firm a stepping stone to open employment? A significant proportion of the participants expressed the view that they did not want to work in the open labour market while some saw it as an ideal opportunity to build up skills to enable them to take this step. One of the participants was working full-time in a social firm having done so for a number of years. She expressed the differing possibilities well, noting that despite working for nearly 10 years she did not feel ready to take the

³⁹ Over 60% of social firms in UK – p12 [Introducing Social Enterprise, Social Enterprise London](#)

step to work in the open market, yet, in her time in the social firm she had seen several people move on successfully. She saw one of the advantages of a social firm being that it could provide both types of opportunities.

Another issue relating to work within a social firm was the potential to earn wages. The participants saw this as central. The feeling was that getting paid for work was crucial. In one of the focus groups there was a discussion about how much should be earned and participants were unsure about this. There was more of a consensus over the need to be paid. Within one group the possibility of being paid part in benefits and part in wages was discussed. The participants identified this as a sensible option as it would provide a safety net if they relapsed.

The participants also saw the ability to engage in real work as vital. Discussions revolved around the type of work that those people who worked in social firms did and it was clear that there was value to what they did. Other participants stated that it was the sense that the work was 'real' which had prompted many to get involved in the development activity for new social firms.

4.9.5 Support Needs in Open Employment

"...if you get back on Job Seekers you're under pressure right away and you're liable to cave in ... whereas if there was some sort of steady rise back into employment then you're not going to break down and you'll be paying your taxes."

"Once you are out on your own and it's 2 or 3 years down the line there won't be any support if you need it then."

"Employers put people under pressure and you need some sort of regular health check at work."

"Employers should do something about helping people to keep their jobs."

"It's really difficult for people at work to try and cope with someone who doesn't know they're ill. It's better to get to know yourself when you're not well and you can try to do something about it."

Most of the participants had experienced difficulties in the workplace in the past and had strong views about the lack of support they had received from

their employers. These discussions were linked to the previous comments on job retention support.

Participants felt that the pressures of open employment were very high for people who had mental health problems and that it would be much more realistic if there was an opportunity to make a gradual transition into the workplace or if they were able to work full-time/part-time within a supportive environment.

Participants identified a need for a greater awareness of mental health for all levels of staff as one of the key issues to make work in open employment possible. This lack of mental health awareness was identified as contributing to the existence of stigma and discrimination. As discussed before, it was the fear of ongoing discrimination and stigma that put many off returning to the open labour market.

Participants thought there was a need for employers to take more responsibility to keep an individual's job open and develop job retention policies. They felt that there should be some form of support within the workplace. Individuals who needed it should receive ongoing support which should include some form of early detection plan so that it was possible to prevent a deterioration into ill health. For this to work individuals would need to try to develop knowledge of their own problems so that they could link into the person responsible for providing their support.

4.10 INTERVIEWS WITH ORGANISATIONS⁴⁰

Interviews were carried out with managers and staff in the field of employment and mental health. Practitioners from the organisations outlined below participated in the interviews:

- Two voluntary sector organisations that provide employment support services for people with mental health problems and another that runs several social firms providing support for people with mental health problems.
- An occupational psychologist working within the statutory services sector (Jobcentre Plus) who advises clients from the whole spectrum of referral points including Jobcentre Plus, hospitals, social firms and voluntary sector employment support organisations.

⁴⁰ [In the employment and mental health field.](#)

The interviews followed up the themes raised within the focus groups. The purpose of the interviews was to find out to what extent the themes were apparent to practitioners in the field of employment support.

There was a congruence of views expressed by participants in the focus groups and practitioners in the field.

4.10.1 Employment is a Health Issue

Participants stressed the need for early intervention and support at the earliest possible stage to try to prevent the downward spiral of ill health, unemployment and continuing ill health. Practitioners also identified the inter-relationship of employment and mental health. From the perspective of the supported employment practitioner, where project staff have been able to provide support to clients who are in employment at the onset of problems, the spell of illness was considerably reduced. This had meant that it was possible to negotiate with the employer the retention of the job that may otherwise have been lost. This type of early intervention requires that both the client and project staff understand the first signs of illness for that individual, that the employer is understanding and that the right kind of support is provided at the right time.

4.10.2 Stigma

Participants and practitioners both highlighted the stigma that exists in employment against people with mental health problems and emphasised it was a major barrier to employment.

4.10.3 Motivation

Many of the participants expressed the view that they wanted to work and gave a wide range of reasons why they thought employment was a very important element of life. The reasons for working varied as did the needs of individuals when it came to progressing from unemployment to some form of work.

Practitioners recognised that many service users want to work. However, within that desire lies a range of individual needs, circumstances and motivation. In practice, clients are looking for a range of opportunities related to employment including further education, employment-related activity, voluntary work, supportive work, supported employment and open employment. These are not necessarily seen as stages on a continuum or a series of steps on a ladder of progression. It is common, for example, for

some clients to start supportive work, become comfortable in that environment and remain there.

In order to progress into employment there needs to be a strong motivation to work on the part of the individual and it was seen as important for clients to take responsibility for themselves in the process of transition. Supported employment could help to ease that process.

4.10.4 The Benefits System

There was considerable overlap and agreement between participants in the focus groups and practitioners that the Benefits System is a major barrier for people with mental health problems taking up employment.

Practitioners agreed that the Benefits Systems placed restrictions on their clients. They expressed the view that some of their clients were motivated to work or progress towards work but did not do so because of their fears arising from the complexities and rigidity of the Benefits System. These fears concerned the whole range of work-related options.

Although the new Permitted Work Rules and Disabled Persons Tax Credit had helped to some extent, the major issues for people with severe mental health problems were largely unchanged.

4.10.5 Supported Employment Services – Gaps in Provision

Participants and practitioners highlighted that the nature of mental health itself had a significant impact on employment prospects and also had implications for service delivery. People classified within this target group have a very wide range of individual circumstances and needs.

In practice, it was highlighted that some people have a recurring health problem which has huge implications when it comes to obtaining employment. It may be possible to negotiate a work placement but the underlying problem is still there. Also, many clients have had very stressful and negative experiences of employment which in some cases actually contributed to or caused their mental health problem. Therefore, there is a strong possibility that they will find it hard to cope with stress in the workplace in the future. For these reasons practitioners have found that support in the workplace, with the objective of maintaining employment, is absolutely vital.

Practitioners identified a number of gaps in the current provision and these are outlined below:

- There is an information gap and clients do not know what services are available in their area. There is a need for a directory of services and signposting.
- There is a need to create a better understanding of the nature of mental health and employment-related issues in all of the institutions, agencies and organisations involved in the area. These include:
 - Psychiatric Hospitals and other health care organisations,
 - Social Work,
 - Further and Higher Education,
 - Careers Scotland,
 - Jobcentre Plus
 - and voluntary sector support organisations.
- There is a need for more resources to enable organisations in the voluntary sector to provide services for a 'gradual transition' to work. Pushing clients through a process which requires a large degree of flexibility is not effective.
- There is a shortage of voluntary sector organisations that provide the comprehensive range of employment support services identified by clients to help them to move away from the 'revolving door syndrome'.
- There is a need for more social firms. Social firms provide a supportive environment within which people can develop work routines and skills. Social firms also provide a stepping-stone to open employment for people who want to go down that route.
- There is a need for a constructive work-related option for people with severe and enduring mental health problems or with high dependency needs.
- There is a need for partnership working within the mental health and employment fields. There are many boundary issues between the major institutions: local authorities; health service; social work; and employment-related services. The various agencies and organisations have different roles, different strengths and different weaknesses. It is

important that service providers come together where appropriate and pool resources in the interests of clients.

4.11 SUMMARY

The data has been presented and analysed. A range of themes has emerged from the focus groups that have been discussed. Information from interviews with practitioners in the mental health field has been outlined in relation to those themes. The following section will address the conclusions of the research and make recommendations based on the research results.

5. CONCLUSIONS

It is recognised that the small-scale nature of the research study affects the generalisation of the results obtained. Despite this, the research study has identified areas where there was consensus of opinion from the participants. These conclusions are discussed and are followed by a series of recommendations.

It was clear that the participants all valued the role work or employment played in their lives and they were motivated to work. Although the participants clearly expressed differences of opinion on their concept of work it was also evident that the participants were at a wide range of stages in terms of their job readiness and ability to sustain employment (whether this was supported, full-time, part-time, within a social firm etc). This issue, in itself, is one that needs to be addressed by policy makers and those providing services.

5.1 EMPLOYMENT AND HEALTH ARE CLOSELY LINKED

Previous research studies have demonstrated the link between employment and health (Durie 2000). Work can be a route out of poverty, leading to an economically active and healthier life. Conversely the link between unemployment and poor health is well established. The recent Department of Work and Pensions Consultation Paper⁴¹ stated that long-term unemployment can lead to a decline in both physical and mental health. This research has reinforced that participants see a perpetuating circle where people develop mental health problems (sometimes through severe stress at work) which leads to unemployment, poverty and continuing ill health.

There is evidence from other small-scale studies (McKeown et al)⁴² that work can improve mental well being and lead to a reduction in use of health services. The perception of the participants in this research was that their health improved when they were in supported employment activity. Although this perception was not analysed in detail and hence is not robust enough to be firmly concluded, it does raise a hypothesis surrounding the potential role of supported work that is worthy of further detailed investigation.

It was also suggested that early intervention and support provided either at hospital, in the community, through employment-related activity or in the workplace could prevent people becoming caught in the downward spiral of ill health and poverty. Given the large number of people with mental health

⁴¹ Pathways to Work: Helping People into Employment, Department for Work and Pensions, (2002).

⁴² McKeown, K, O'Brien, T, & Fitzgerald, G, The European Project on Mental Health in Ireland (1989-1991): An Evaluation.

problems who are excluded from the labour market this is a social inclusion issue of major significance and should be a matter of priority for the Social Justice agenda.

The researchers also identified another pattern emerging in regard to motivation. As discussed, the participants were motivated to work but there was a distinction that emerged within this. Many of the participants were 'clients' of the health service and their motivation was towards employment-related activity within supported settings. They did not aspire to work in the 'open' labour market, instead they sought refuge from this within supported settings. Despite the lack of desire to move towards the open labour market, there was a desire to contribute within the supportive work settings that these participants were engaged in. This group saw value in the work they were offered and gained value from engagement in this employment-related activity. This group saw employment-related activity as a 'health choice' in terms of the type of health provision they felt they required.

Conversely, a smaller group of the participants were motivated towards employment. They aspired to work in the open labour market and saw their mental health problems as an issue that had to be dealt with to obtain what they desired. If this group had to be described then they could be viewed as people who had made an 'employment choice' but had health problems that were a barrier to fulfilling this.

This differentiation in motivation and aspiration appeared significant to the researchers in terms of the types of service provision that the participants were describing that they needed as well as the barriers they faced. As above, this hypothesis is not robust so it cannot be concluded that services for people with mental health problems should be shaped along these lines but the issue of motivation and aspiration and whether clients view employment as a health choice or an employment choice is worth further exploration.

5.2 STIGMA

It was identified that the stigma associated with having a mental health problem was a significant barrier. Many, if not all, of the participants had experienced discrimination due to the stigma of mental ill health. It was further identified that stigma was perceived to exist to some extent in many of our institutions, particularly in employment at the recruitment stage and in the workplace at all levels within companies. Again, it is impossible from the research to quantify this but the researchers were struck by the depth of feeling that many of the participants attached to their experiences of stigma. This was particularly prevalent for those seeking to move into open

employment where there was a fear of disclosure due to a perception of negative response.

The researchers recognise that the significance of the issue of stigma has been identified at Scottish Executive level and is being tackled through the 'See Me' campaign. The evidence from the research would point to the need to persist with health education campaigns of this nature and also to look specifically at how mental health awareness could be raised within the workplace in order to create a better understanding of mental ill health and tackle one of the clear institutional barriers causing employment exclusion.

5.3 JOB RETENTION

Although not a significant aspect, the research highlighted the amount of stress participants had experienced in the workplace and the negative impact the effect of this stress had on their mental health. Stress is a health and safety issue and it is important that employers take action to reduce stress in the workplace. This involves identifying the causes of stress and ensuring that support mechanisms are established.

Given the number of participants who had dropped out of work due to their mental health problem, it was suggested that employers should consider the advantages of developing job retention policies for staff who develop mental health problems. There is a need for ongoing support in the workplace. One of the possibilities is to foster 'natural' supports in the workplace, through increasing knowledge and understanding of mental health issues. The aim would be to provide an early warning system to prevent, where possible, deterioration into ill health.

5.4 THE BENEFITS SYSTEM

The research adds to the growing body of evidence that the Benefits System is one of the major barriers to employment for people with mental health problems. It was concluded that a number of specific changes to the Benefits System are essential to enable people to move from unemployment into employment. The need for changes highlighted in the research are in response to the need to deal with the current complexity and inflexibility of the Benefits System. Previous research (McCormack 2001, Durie 2000, New Futures Fund Initiative 2000) has highlighted the inflexibility of the system as significant. The participants in this study echoed that view in relation to employment-related activity and moving towards employment.

5.4.1 Job Start

It was clear for those considering open employment financial assistance is needed to cover the costs of job seeking and initial work-related expense. Although there are small grants available for this purpose they tend to be discretionary and not well known. An accessible, well publicised grant which does not affect other benefits is needed. The researchers are aware that this type of provision has been identified within the recent 'Pathways to Work' Consultation and welcome its proposed introduction.

The above proposal is specific to bridging the barrier for those making the immediate transition from not having a job to starting a job. The other areas identified are broader in scope and address wider issues in terms of what the participants identified as crucial to make the transition from economic inactivity to employment.

Many of these issues have been identified within previous research studies and the researchers conclude that there is sufficient evidence for the need to significantly alter the current Benefits System. At the root of this conclusion is the philosophy that underpins the Disability Discrimination Act – that of 'reasonable adjustment'. When looking at the experiences of the participants the researchers concluded that with 'reasonable adjustments' to the Benefits System, people with mental health problems would have a significant barrier to employment exclusion removed. As discussed, the specific actions that were identified have been well documented by other researchers and hence are presented in bullet fashion.

5.4.2 Action to reduce complexity of the Benefits System

- Provide specialist advice from advisers that people can trust who have the technical benefits knowledge and an understanding of mental health problems tailored to the needs of individuals.
- Ready availability of accurate work/non work benefits comparison that includes accurate analysis of full 'in work' costs.
- Introduce safeguards for benefits recipients for wrongful or misleading advice.

5.4.3 Action to improve the flexibility of the Benefits System

- Increase the number of hours people are allowed to work. The interaction of the earnings disregard and the 16-hour rule is restrictive and prevents people steadily increasing the hours they work to build up stamina in work and progress towards employment full-time at 35-40 hours.
- Address the issue of the links and tapers which create the interaction between Housing Benefit/Council Tax Benefit and other disability benefits.
- Create a mechanism within the current system which allows people to participate in employment-related activity with the minimum of bureaucracy yet combine this with the possibility to earn some income.
- Allow for flexibility for fluctuating health and permit a person to move in or out of employment without penalty.
- Introduce a more comprehensive step-up phase to enable people to make a gradual adjustment to employment.
- Create a mechanism within the current system which allows for a clear benefits, wage and tax interaction which supports a culture of progression towards work.

5.4.4 Mental Health Awareness Training

- Training is needed to create a better understanding and awareness of mental health for staff within the Job Centre Plus.
- Given that the statistical evidence is of the significant numbers of people with mental health problems on incapacity benefits then this training should be a priority issue for all front line staff.

5.5 EMPLOYMENT-RELATED ACTIVITY

There was evidence from the experience of the participants of the value of employment-related activity. Many of the participants were, or had been, engaged in activity (social firms, clubhouses etc) which they saw as therapeutic and supportive but which they did not see as being a gateway to

the open employment market. This conclusion relates to the earlier hypothesis of participants making 'health choices' or 'employment choices'.

One of the key characteristics of this employment activity was the lack of perceived stigma. Participants identified that they were often engaged in this activity within supportive working environments. Discussion of the nature of these supportive working environments identified clear characteristics that participants saw as necessary for developing good services. A discussion of the effect of these supportive environments revolved around improved self-confidence, greater self-esteem, less isolation and an improved sense of well being. The researchers are aware that the nature of the research denies a robust analysis of these 'soft' indicators but again note that there is the emergence of another hypothesis that requires further investigation.

One of the consistent barriers to engagement in employment-related activity was "fear". The participants, most of whom had severe and enduring mental health problems, repeatedly expressed concern about how the 'Benefits Agency' would view their choice to attempt to place some structure in their lives through these activities, concern over the bureaucracy necessary to engage in the activities and the impact of attempting to earn small amounts of income through these activities.

The researchers concluded that there is the need for a first step into employment opportunity that allows people (not just those with severe mental health problems but encompassing a wider group of disabilities) to engage in activity without the weight of state bureaucracy interfering in these decisions.

5.6 MOVING TOWARDS EMPLOYMENT

One of the main issues to emerge from the research was the gap in provision that exists to enable people who have mental health problems to progress towards employment. Previous research (Durie 2000, Pressland 2000, Forth Sector 2002) has identified these gaps as existing within the following areas:

- Lack of a clear pathway to progression.
- A lack of opportunities for people to take the first steps in employment and/or engage in employment-related activity.
- A wide range of personal barriers to progression.
- Institutional barriers to progression, primarily based on stigma and discrimination.
- Structural barriers to progression that revolve around the inflexibility of the current Benefits System.
- Patchy provision of support to assist people to progress.

These factors interlink with each other and the effect of this is to reinforce the sense of employment exclusion.

The research has been titled 'Mind the Gap' in response to a new conceptual framework that emerged for the researchers. As indicated, the researchers commenced the research with the view that there were personal, institutional and structural barriers and influences that needed to be addressed to help people with mental health problems to progress towards employment. This conceptual framework has been reinforced by listening to the experiences of the participants.

The issue surrounding personal barriers is discussed more fully below. What the researchers found significant was the weight that the participants attached to the issues of stigma, lack of awareness of mental ill health and the Benefits System. These factors are institutional and structural barriers. The researchers were left with the impression that the participants frequently saw these barriers as insurmountable and daunting.

Early in the research process the researchers discussed the formation of a new conceptual framework. From this ongoing discussion of the 'journey' that the participants moved through towards employment emerged the title of the research. Previous research (Durie 2000) has identified that the employment provision for people with mental health problems within Scotland is patchy and inconsistent. Although Durie identified centres of good practice and effective models of care, it was clear there is a 'postcode lottery' in terms of the provision of this type of 'employment care' within Scotland. This view was reinforced by the research where the participants linked together their experiences to identify gaps in service provision and gaps in support.

One of the clear 'support gaps' was the lack of effective working between the statutory health care providers and the employment service to address support needs and deal with barriers to progression. The researchers are aware that in other parts of the UK joint care planning between the health service and the employment service is more structured⁴³ and that the Department of Work and Pensions have recently advocated closer work as part of their review of incapacity benefits.⁴⁴ These moves are welcome and the researchers conclude that effective joint working will narrow one of the gaps.

Yet the researchers also identified that much of the support offered to the participants in the research was located within voluntary organisations not statutory provision. It is concluded from this that there needs to be far more

⁴³ Butterworth, R, Dean, J, (2000), Putting the Missing Rungs into the Vocational 'Ladder', Volume 4 Issue 1 A life in the day.

⁴⁴ Pathways to Work: Helping People into Employment, Department for Work and Pensions, (2002).

statutory and voluntary collaborative working to ensure coherence of service provision.

Added to this was the clear gap existing within the legislative framework of the current Benefits System to allow people with severe mental health problems to engage in meaningful work. The researchers recognise that the government and the Department of Work and Pensions have taken significant steps to close this gap through recent welfare to work reforms. Yet, it is still the case that research studies highlight the inflexibility of the system as a key barrier. Although the purpose of the research was not to quantify any barriers that existed it was evident to the researchers that the lack of an appropriate legislative framework in terms of benefit provision for those seeking to engage in employment-related activity and supportive work is perceived to be the most significant barrier.

The issue is that people with mental health problems do not perceive the Benefits System, or those that administer it, to be "on their side" and supportive of the steps they have to, or want to, take to move towards employment. This perception is deep rooted and is backed up by a mass of personal experience, prejudice, misinformation, distrust and discriminatory practice. The gap between where people with severe mental health problems perceive themselves to be in terms of access to employment and where they want to be is significant. The researchers concluded that bridging that gap will take legislative action as a first step.

Perhaps the most poignant 'gap' that was identified was not specifically related to legislative framework, service provision or to support provided. It was an '**opportunity**' gap. What emerged from the experiences of the participants was a sense of exclusion from a range of areas of society due to the stigma surrounding mental ill health. It was also clear that the participants saw their exclusion from employment as significant in terms of the perpetuating of a cycle of poverty, continuing ill health and a lack of opportunity. If the experiences of the participants are replicated throughout the experience of people with severe mental health problems in general then this is not only an employment exclusion issue but a **significant social justice** issue. The conclusion of the researchers was that the 'gap in opportunity' was as significant as the gaps that exist in legislative framework, service provision and support.

5.7 EMPLOYMENT SPECTRUM

Closely linked to the hypothesis that the participants' motivation towards work was related to whether they were making a 'health choice' or 'employment choice' was evidence of the need to develop the transitional employment market⁴⁵.

The researchers are aware of a vast range of employment provision existing and emerging within the UK, including occupational therapy units, enterprise projects, sheltered workshops, training projects, clubhouses, social firms, intermediate labour market projects, user-run businesses, employee development projects, etc. This provision is outside of mainstream Jobcentre Plus service provision. This led to the development of a provisional 'employment spectrum' as follows:

Employment-related activity – Including voluntary work, supported education projects, vocational training projects, etc.

Sheltered Employment – Including 'sheltered workshops', 'occupational therapy units/programmes', 'in-house' clubhouse activities, enterprise projects, etc.

Transitional Employment Market – Including 'intermediate labour market companies/ projects', social firms, user-run businesses, transitional employment placement schemes (clubhouses), 'new futures fund initiatives', etc.

Job Brokerage – Including 'New Deal for Disabled People', 'Job Introduction Scheme', 'Work Preparation', etc.

Employment Support – Including 'Workstep', 'Access to Work', etc.

Job Retention – Occupational Health Schemes, Employee Assistance Programmes, etc.

It was recognised that this 'employment spectrum' is not specific to people with mental health problems but is pan-disability. In addition it was recognised that the types of provision outlined in the spectrum should include the range of hybrid versions of the various models that exist

⁴⁵ The researchers are aware that this has at points been labelled the 'alternative labour market' but believe that 'transitional' is a more appropriate term. As indicated in the research review this transitional employment market is already in operation but is small scale with patchy provision throughout the country.

The researchers also identified that the funding of this Employment Spectrum is primarily within the domain of the public sector, with the health/social care sector providing the majority of funding for the employment-related activities and sheltered employment and the Department of Work & Pensions providing the majority of funding for the Job Brokerage and Employment Support. The Transitional Employment Market is located primarily within the social economy⁴⁶ and hence does not have access to the high levels of mainstream funding.

It is also the case that most of the service provision within the Transitional Employment Market is innovative and new and, hence, it is fair to say relatively untested in terms of robust evaluation. It was also evident that some of the provision within the 'sheltered employment market' had been influenced by the innovation and good practice within the Transitional Employment Market and was attempting to adapt and provide more socially inclusive working environments⁴⁷. Despite the small scale nature of the Transitional Employment Market and the limited coverage of models such as social firms, there are 'centres of excellence' for each of these models within the UK and there are often strong links with well established models in other European states or the USA where robust evaluation has provided evidence of successful employment provision.

The researchers are aware that one of the criticisms of aspects of the transitional employment market (particularly intermediate labour market projects and transitional employment schemes) is that it is too expensive. This criticism has to be viewed alongside the cost of maintaining the status quo where millions of people are economically inactive and dependent on a Benefits System that is increasingly expensive to maintain. As discussed, Schneider (1998) sees a clear case for the transfer of expenditure away from maintaining people in economic inactivity towards engaging people in employment-related activity. Heyman et al (2002) and Thomas (2002) have both reviewed research studies that present a case for the cost-benefit of this approach.

Against this backdrop, it was apparent to the researchers that those participating in the research were predominantly involved in this Transitional Employment Market. What was clear to the researchers was that these participants placed great value on the support they received. The researchers were also able to deduce that the key characteristics of the supportive working environment identified earlier were the factors behind this. It was apparent that the participants were advocating for the extension of this type

⁴⁶ Voluntary organisations and social enterprises

⁴⁷ This is apparent in the attempts at transformation by a number of enterprise projects into emerging social firms and the moves towards externalisation by occupational therapy units, day centres and some sheltered workshop provision.

of service provision. This has implications for health provision, employment provision and the Benefits System in the UK.

Durie (2000) identified that there is no uniform provision of employment-related services for people with mental health problems throughout Scotland. The postcode lottery of provision has been discussed, in that new models of care such as social firms do not exist in every area of the country.

The health service has recently been incorporating the notion of service user involvement into the planning and commissioning of new services. The researchers believe that the qualitative nature of this research adds weight to the argument that each health authority should be looking at new models of care, such as social firms, for people with severe mental health problems who are 'clients' of the health service but want employment-related activity. Schneider (1998) argues this point, noting that some of the current costs of keeping people with mental health problems economically inactive could be better redirected into services to help them gain and retain employment.

The researchers believe that the long-term advantage of the health service moving away from traditional approaches towards new models such as social firms is, not only are they meeting 'customer demand' but given the cost-effectiveness of social firm provision there will be inevitable cost savings. The researchers are not familiar enough with the costing structures of other new models such as user-run businesses or clubhouse (transitional employment schemes) to put forward a conclusive argument in this area but believe the research places an onus on health authorities to look at alternative models.

The researchers are aware that one of the consistent barriers identified in terms of development of social firms, intermediate labour market companies, transitional employment schemes etc is the Benefits System. The effect on individuals with severe mental health problems and the action required has been discussed previously. The effect on organisations developing new projects is again complex and involves the interrelationship between trying to provide health care within an employment setting. The researchers are aware from previous research (Pressland 2000) that many organisations are stuck in a cycle of offering perpetual training, limited working hours, low wages, lack of suitable transitional arrangements, no sense of a 'real job' or no opportunity to progress. One of the impacts of this 'benefits trap' for organisations is the criticism that the new models of care do not work. This criticism cannot be skirted because in many cases this is true. Yet, it is the case that when a model is analysed outwith the restrictive setting of the UK Benefits System, it is shown to be effective.⁴⁸ While the focus of activity within the Department of Work and Pensions is, rightly, on how to get those closest to the labour market off benefits and into employment, the

⁴⁸ Hatch, S, (1994), *Why Social Firms Succeed in Germany But Not In Britain*, Westminster Association for Mental Health, London.

researchers believe there is a need to ensure that any 'incentives' within the current system for one group do not discriminate, even by default, against others and reinforce a sense of continued employment exclusion.

The recognition and potential impact of the Transitional Employment Market may also indicate that there is a need to extend the concept of 'supported employment'. This notion was argued by Grove et al (2000)⁴⁹ when looking at the supported employment framework for people with learning difficulties. From the focus groups there emerged limited evidence of social firms successfully offering full-time supported places to people with mental health problems as part of the Workstep Programme. The researchers believe that extending the current Workstep Programme beyond the current restrictive boundaries of working hours and into the Transitional Employment Market would provide the platform for a more inclusive approach that allows those who want to work but need some support, to be able to. Again, the researchers are aware that the evidence from the research does not provide a robust case for this but believe that the research case has been steadily built for the need to increase the range of supported employment and that the Department of Work and Pensions should look to actively 'pilot' initiatives in this area.

5.8 BARRIERS TO EMPLOYMENT

The primary structural and institutional barriers to people with severe mental health problems accessing employment and ending employment exclusion have been discussed. It was evident from the research that the participants saw a range of personal barriers existing that prevented them from gaining employment or progressing towards that goal. As expected each participant had their 'own story' and set of experiences that contributed to their own personal set of barriers. The researchers do not believe it would do justice to the experiences of the participants to list the various barriers highlighted without the context.

What was evident to the researchers was that there was a range of barriers and that they differed from person to person. The researchers also hypothesised that the personal barriers were likely to be affected by fluctuating ill health, fluctuating motivation and individual self-awareness. These factors make the assessment of people a complex interaction. The researchers concluded that further activity is required to develop appropriate methods of assessment to allow both the individuals themselves and the professionals that work with them to assess the service required to assist progression.

⁴⁹ Grove, B, Byer, S, Leach, S, O'Bryan, A, Simons, K, (2000), Ideas for Developing Supported Employment: A Draft Consultation Document, The Policy Consortium for Supported Employment.

5.9 EARLY INTERVENTION

Finally the need for early intervention at the first signs of illness, either in hospital or at the workplace was highlighted as a priority in the research. The participants identified this could make a huge difference and help people to regain control of their current lives before they become caught in the perpetuating trap of social exclusion and ill health.

Although this was not a significant aspect of the research results it was clear from analysis of the experiences of the participants that early intervention did not occur. The perception of the participants was that re-engagement with employment was seen to be bottom of the list by the health professionals despite the priority set on it by those with mental health problems. Thomas (2002) categorically states that 'in-work' support is needed for people who develop mental health problems to enable them to retain employment. She concludes that the current gap in job retention services is resulting in increasing numbers of people losing employment due to mental illness and becoming dependant on Incapacity Benefits.

The researchers tentatively suggest that closer partnership working between GPs, health care staff, employment providers and the employment service may assist in developing appropriate early intervention strategies. Thomas (2002) has made a fuller list of recommendations in this area.

5.10 RECOMMENDATIONS

Many of the recommendations have been woven into the discussion of the conclusions of the research. This is because the researchers are aware that further work is required to test the numerous hypotheses that have arisen from this qualitative study. The need for further research and piloting of activities is central to the recommendations made.

5.10.1 Flexibility

Echoing previous research, this study recommends that if the aim is increasing the numbers of economically inactive people, on Incapacity Benefits, into the labour market then there needs to be increased flexibility within the Benefits System.

It is too simple to say that the Benefits System does not work. For millions of people it provides a safety net that is essential. This is in line with the government's Welfare to Work policy imperative of "...support for those who cannot."

However, it is clear that when viewing the Benefits System through the prism of encouraging people on Incapacity Benefits who want to work, can carry out (some) work and providing them with the mechanism to be able to do this; then the Benefits System does not work.

To create the environment where the 2nd of the government's Welfare to Work imperatives – "Work for those who can....." is achievable then flexibility within the system is essential. People must have the opportunity to take a gradual 'step-by-step' approach to re-engaging with the labour market.

At the root of this recommendation is the recognition that the people with mental health problems who are interested and motivated to work are looking to work in an increasingly flexible labour market. The core theme running through the focus groups was that, in order to meet the challenges that employment brings for them they need a flexible response from the Benefits System.

5.10.2 Transitional Employment Market

Given the possibility that open employment might not be a realistic option for some people with severe mental health problems combined with the identification that significant numbers of this group want to work within 'supportive working environments' then there should be the recognition of the transitional employment market.

The participants described the value of a range of employment-related activities (social firms, intermediate labour market, transitional employment schemes, etc). Although the transitional employment market might not move people immediately off benefit reliance there was a clear value in its role of supporting people taking these crucial steps towards employment.

The potential advantages of the transitional employment market would be to:

- Give people with severe and enduring mental health problems the opportunity to engage in work-related activities.
- Reduce employment exclusion and create a culture where work is seen as a preferred option.
- Provide potential health benefits and reduction in health service costs through involvement in employment programmes.

- Reduce social exclusion for groups of people.

While this step would have no immediate impact on the numbers of people claiming benefits it is recommended that the Department of Work and Pensions introduce reform to the Benefits System to remove the barriers to the growth of the Transitional Employment Market.

It is also recommended that the Department of Health as well as Social Services Departments look to pump prime the transitional employment market through the funding of nationwide initiatives to develop social firms, intermediate labour market projects, transitional employment schemes, etc.

Although there is the criticism that these activities have not been robustly researched, this has to be considered alongside the clear evidence that current provision is not working. Given that the Department of Work and Pension's own consultation paper has identified that the longer someone is out of work the less likely it is that they will find work then it is clear that the status quo cannot be an option.

It is recommended that this funding of the Transitional Employment Market is run in parallel to the research programme outlined below.

5.10.3 Interdepartmental and Partnership-Working

Given that the employment of people with mental health problems is clearly both an employment/benefits/tax issue and a health issue then there needs to be a strategic commitment to interdepartmental working between the Treasury, the Department of Health, the devolved administrations and the Department of Work and Pensions. These agencies should also seek to develop partnership working with employment intermediaries to shape the evolving policy agenda.

A focus of the interdepartmental partnership working should be to address the personal, institutional and structural barriers to employment for people with mental health problems. The aim of this would be to also remove the gaps in service provision and support offered. Action should create a legislative framework that encourages opportunity and reduces exclusion.

5.10.4 Further Research

Given the identified scale of the problem of employment exclusion for people with severe mental health problems then further strategic research is required to inform the developing policy agenda. This research should include:

- Large scale study into the employment experiences of people with severe mental health problems.
- Quantitative analysis of the job readiness of unemployed people with mental health problems and analysis of/comparison with service provision to this group within a defined locality.
- A large scale cost-benefit analysis of different types of employment provision.
- A health benefit analysis of people with severe and enduring mental health problems engaged in employment programmes.
- An 'Action Research' programme to pilot actions to increase flexibility within the current Benefit System.

5.11 CONCLUDING REFLECTIONS

5.11.1 Margaret Pressland, Forth Sector

As one of the researchers, a major aim was to find a way of initiating a full and open discussion with service users about the issues of mental health, employment and welfare benefits. It was, therefore, important to have the involvement of service users throughout the process. This was carried out through the contribution of an advisory group, which included services users, practitioners who were involved at the planning stage of the research and the participation of people with mental health problems in the focus groups.

The advisory group planned the design, content and methods to be used in the focus groups. The advisory group also recommended that participants should be reached by linking up closely with support organisations who would then make the contacts with their clients and publicise the focus groups. The methods to be used in the focus groups were to be as interactive as possible and it was decided to use the method of 'graphic facilitation'. This would encourage interactive discussion and the visual aspect of the recording would make it possible for participants and facilitators to agree the main points.

I believed the aims of the research would be met by this approach. However, I was aware that a number of important elements would have to come together at the time of the focus groups for it to work. The elements included: that there were a sufficient number of participants attending for a discussion to take place, that the right environment was created on the day

where participants felt they could discuss their personal experiences and the discussions were facilitated in a way that encouraged a free flow of ideas at the same time as being relevant for the research.

As it turned out, the main elements did come together and, from my perspective, I thought that the focus groups worked well. They were well attended, had a supportive, informal environment and participants were able to outline and explain their experiences in depth. The discussions were also well focused on the issues of mental health, employment and benefits.

The issues raised within the focus groups were probably what could have been expected and many of them have been identified in previous research. However, the basis for developing a case for lobbying is very compelling when told from the perspective of the people who are affected by the situation.

I think the aims of the research were achieved and one of the main reasons was the contribution of the advisory group. The meetings that took place with the advisory group did extend the planning stage of the research. However, it was well worth it in terms of the quality of ideas and experience that were brought to the research.

5.11.2 Kevin Robbie, Forth Sector

In reflecting on the process the most illuminating aspect was the willingness of, and the enthusiasm from, the participants to engage in the research. As a research team we had started with the concept that there were personal, institutional and structural barriers that reinforced the employment exclusion of people with mental health problems. Through the research this concept was confirmed and also added to. The participants, through talking about their experiences, sketched in a pattern of service provision where there were clear gaps. The participants saw these gaps existing at a number of levels. They spoke of the gap in support offered but also more passionately about the gap in opportunity because of the barriers that exist.

We would want to thank all of the participants for their involvement and contribution without which this research study would not have been the rich experience it was.

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CONTRIBUTORS

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APPENDIX 1

PARTICIPANT PROFILES

Mr A (1) is in his early 50s and lives in Aberdeen. He has been unemployed for 6½ years. Mr A has mental health problems and is in receipt of Incapacity Benefit. He is currently attending an IT training course with a local support project and is also receiving support from staff at the project.

Ms A (2) is in her early 40s and lives in Aberdeen. She has been unemployed for approximately 6 years. Ms A has mental health problems and receives Incapacity Benefit and the Disability Living Allowance. She is currently engaged in voluntary and training activities. She carries out voluntary work as a word processor operator and is attending the local College to take the European Computer Driving Licence. Ms A is also studying at University on a part-time Breakthrough Course. She is receiving support from several local support projects.

Ms A (3) is in her mid-50s and lives in Aberdeen. She has experienced mental health problems and has been unemployed for four months. She is unsure about her situation with regard to her eligibility to receive Benefits. She currently attends a local support project.

Ms A (4) is in her early 40s and lives in Aberdeen. She has been unemployed for 4 years. Ms A has mental health problems and is in receipt of Incapacity Benefit, Housing Benefit and Council Tax relief. Ms A is currently undertaking training in IT and attends a local support project three half days each week and the local College one afternoon. She is receiving support from the local support project.

Mr A (5) is in his late 40s and lives in Aberdeen. He is currently self employed. Mr A has experienced mental health problems and is receiving Incapacity Benefit.

Ms A (6) is in her early 30s and lives in Aberdeen. She has experienced mental health problems. Ms A is currently a student and is not in receipt of benefits.

Mr A (7) is in his early 50s and lives in Aberdeen. He has been unemployed for 10 years. Mr. A has mental health problems and is in receipt of Incapacity Benefit. He is currently undertaking training in IT and Administration.

Mr A (8) is in his in his 40's and lives in Aberdeen. He has been unemployed for less than 6 months. Mr A has mental health problems and is in receipt of Incapacity Benefit. He is currently taking part in some voluntary work at the local school.

Mr G (9) is in his mid-50s and lives in the Glasgow area. Mr G has mental health problems and is unemployed. He is in receipt of unemployment benefit.

Ms G (10) is in his mid-40s and lives in Glasgow. She has been unemployed for 6 years. Ms G has mental health problems and is in receipt of Incapacity Benefit. She is currently undertaking the European Computer Driving Licence Course at the local support centre that she attends.

Mr G (11) is in his late 50s and lives in the Glasgow area. Mr G has mental health problems and has not worked for 37 years. He is in receipt of Incapacity Benefit, Disability Living Allowance, and Income Support. He is currently carrying out voluntary activities at a local support centre and receives support from co-workers there.

Ms G (12) is in her late 30s and lives in Glasgow. She is currently working part time. Ms G has experienced mental health problems. She is not in receipt of benefits and does not receive any other type of formal or informal support.

Ms G (13) is in her early 30s and lives in Glasgow. She has been unemployed for over 3 years. Ms G has mental health problems and receives Incapacity Benefit Disability Living Allowance and Income Support. She is not currently undertaking any training or voluntary activity.

Mr G (14) is in her mid-30s. Mr G has mental health problems and has been unemployed for 12 years. He is in receipt of Income Support and the Disability Living Allowance. Mr G attends a local support centre and participates in activities on a daily basis.

Mr G (15) is in his early 30's. He has mental health problems and is long term unemployed. Mr G is in receipt of Incapacity Benefit and takes part in a Transitional Employment Programme which is run at a local support centre.

Ms G (16) is in her 40's and lives in Glasgow. Ms G has mental health problems and was until recently had been long term unemployed. She took part in a Transitional Employment Programme at a local support centre and now works in a supermarket for 10 hours a week on "Permitted Work".

Ms E (17) is in her mid-40s and lives in Edinburgh. She has been unemployed for 4 years. Ms E has mental health problems and is in receipt of Income Support. She is currently carrying out training. Ms E receives support from employment support workers.

Ms E (18) is in her early 50s and lives in Edinburgh. She has experienced mental health problems. Ms E is now employed by a social firm in Edinburgh. She is not in receipt of benefits. She is on the Workstep Programme.

Mr E (19) is in his early 40s and lives in Edinburgh. He has been unemployed for 6 years. He has mental health problems and is in receipt of Incapacity Benefit and Disability Living Allowance. Mr E is currently carrying out therapeutic work/permitted work with a social firm. Mr E receives support from employment support workers linked to the social firm.

Mr E (20) is in his early 50s and lives in Edinburgh. He has been unemployed for 16 months. Mr E has mental health problems and is in receipt of Incapacity Benefit and Disability Living Allowance. He is currently receiving support from a local support project.

TABLES

Table 1 - Influences on Progression Towards Employment

Table 2 - Incapacity benefits caseload by diagnosis group – May 2002

Table 3 - Comparison of numbers claiming key benefits in different client groups with duration of claim