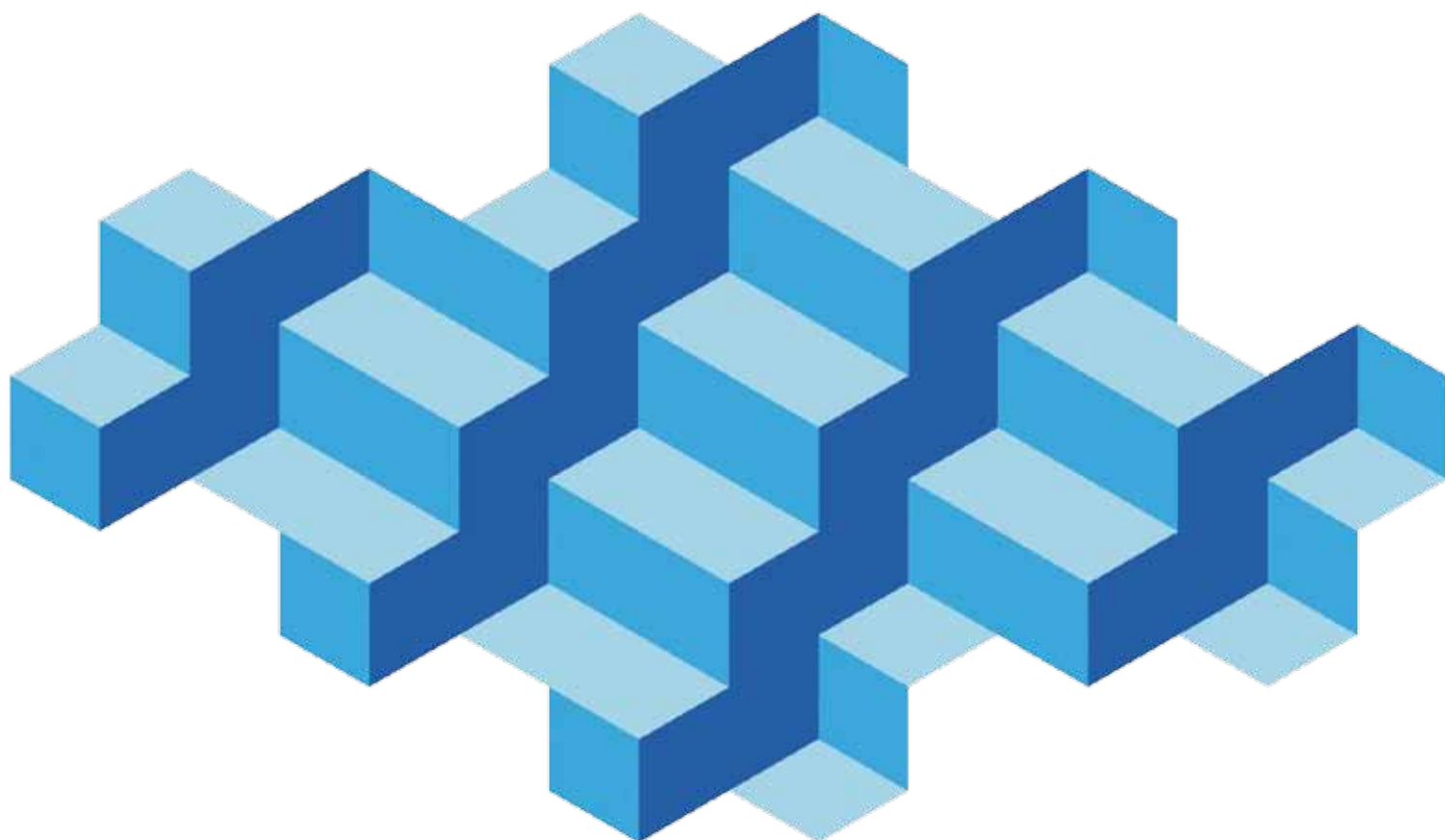


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Working with Schizophrenia:

Pathways to Employment, Recovery & Inclusion

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Foreward



The mental health of the nation is, quite correctly, receiving more attention from policy-makers, clinicians and employers. With 1 in 6 UK workers having a mental illness at some time in their career it is right that we should be paying more attention to the psychological wellbeing of working age people at a time when labour market conditions are tough.

But while much of the attention and resources are directed at important conditions such as depression and anxiety, severe mental illnesses such as schizophrenia remain largely in the shadows. In November 2012 it was my great pleasure to oversee the publication of the final report of The Schizophrenia Commission, of which I was Chair. We chose the title of the report – The Abandoned Illness – with great care, lest we were charged with being alarmist. Regrettably, the weight of evidence was overwhelming and we concluded that, despite some progress, ‘the current system of care and support for people with schizophrenia and psychosis, and their families, is failing both them and the taxpayer’.

An important area of focus for the Commission was on social inclusion and it is clear that, for many people with schizophrenia, having a job can mean a great deal, both economically and socially. Yet people living with schizophrenia have some of the poorest employment rates of any group in the UK labour market. The barriers to employment are considerable.

This is why I very much welcome this report by The Work Foundation because it focuses our attention on the true nature of these barriers to work and how they might be overcome. It challenges politicians, GPs, Psychiatrists, family-members, support workers, employers and people living with schizophrenia themselves to join forces with greater urgency to widen access to the labour market and competitive employment. The picture of the jobs market, and the way it works against people with severe mental illness in the UK, is not pretty. But the report is ultimately optimistic because it indicates very clearly that the solutions to this problem are known, and that good practice exists.

Our challenge is to embrace the lessons from this report and to redouble our efforts to support people living with schizophrenia to find their rightful place in the world of work.

A handwritten signature in black ink that reads "Robin Murray".

Professor Sir Robin Murray

**Chair of The Schizophrenia Commission; Professor of Psychiatric Research,
Institute of Psychiatry, Kings College London**

Executive summary

This report highlights the barriers experienced by people with schizophrenia in the UK to entering and remaining within the labour market, and what can be done to overcome these barriers and to support people with schizophrenia to live full and meaningful lives including employment. Work can be invaluable for those who want it, providing them with a sense of purpose, dignity and social inclusion. **The authors argue that with better co-ordinated support and increased understanding of the condition and the importance of work for recovery, considerably larger numbers of people with schizophrenia could both gain access to, and remain within, the labour market.**

In order to gain an in-depth understanding of how the structural, economic, clinical and attitudinal barriers to employment impact people with schizophrenia, we reviewed previous studies and conducted in-depth interviews with people with lived experience of schizophrenia. In addition, we conducted a number of telephone interviews with experts including healthcare professionals, as well as experts from patient groups, employers, occupational health specialists, employment support services, caregivers and family members

Main findings

Schizophrenia is a severe form of mental illness that affects approximately one per cent of the UK population. The World Health Organisation (WHO) has ranked the condition as the ninth leading cause of disability among all illnesses worldwide, in a large part because of the impact of lifestyle factors (such as smoking and obesity) and high levels of co-morbidity. The condition also creates a considerable social and financial burden, not only for individuals but also for their families, caregivers, the healthcare system and social services.

The onset of schizophrenia most commonly occurs at the threshold of adulthood – when young men and women are likely to be making the transition to independent living. Schizophrenia is therefore seen as having a crucial impact on their educational and employment opportunities. For those who are in work, symptoms of the illness, side effects of the treatment and relapse may affect their ability to remain employed.

Work brings clear health benefits for people with schizophrenia, research shows that those in paid employment are over five times more likely to achieve functional remission than those who are unemployed or in unpaid employment.

A considerable proportion of working age people with a history of schizophrenia are able and willing to work. Despite repeatedly expressing the need for job training, placement and support services, this group encounters one of the highest unemployment rates

among all vocationally disadvantaged groups: The Schizophrenia Commission report identified the employment rate of this group as being around 8 per cent in the UK, within a range of 5 -15 per cent, against a national UK employment rate of 71 per cent.

Low employment rates are heavily influenced by the societal and economic pressures faced by individuals, the reality of the labour market, and psychological and social barriers to working. In times of recession and high unemployment, it is less likely that those with a fragmented work history or lower level of education will be working, especially if they are suffering from a highly stigmatised illness, such as schizophrenia.

There is a general belief that “people with schizophrenia are not able to do things very well” that “they will fail”. Psychologist

Low expectations of society, as well as of people who are close to them, are strong barriers to employment for people with schizophrenia. Discrimination is common, with evidence indicating that as many as 70 per cent of people with schizophrenia have experienced discrimination. This has been linked to high levels of self-stigma, impacting on individual’s motivation to work.

I’ve come across people who have low expectations of themselves because they’ve been told “you’ll never work” or “you’re going to have a life of taking medication and you’re not going to be able to live life to the full”. So I think there are low expectations on people by others as well as by themselves. Psychological Therapist

I’ve got a really negative outlook of work, especially through my experience. Even though you want to work, it is just sometimes the experience of mental health, it just gives you that limitation on what you can handle at work and what you can do and what you cannot do. Lived experience

Even though healthcare professionals acknowledge the importance of work, they often hold the view that people with schizophrenia would be better suited to low skilled and low responsibility or non-competitive work (i.e. voluntary or sheltered). Some healthcare professionals interviewed perceived that certain jobs might be specifically assigned to people with severe mental illnesses, defined as being less stressful roles with greater flexibility. There was also a suggestion that within the health sector the role of employment for recovery is not given priority, and may not even be considered as an outcome by some health-care teams.

On the other hand, many experts support the view that people diagnosed with schizophrenia as a group should not be overlooked for any role because of their condition, but that the abilities and skills of each individual need to be assessed and built upon.

I really think it's about helping to fit the right job to the person rather than the other way around. Nurse Consultant

Feeling better by working –Experiences of people with schizophrenia

People with lived experience of schizophrenia who we interviewed were really motivated to work. In addition to seeing a job as providing a sense of normality, and financial gain, the importance of having a job that they enjoyed was highlighted – for some this was seen as incredibly valuable to their health. This reflects the concept of recovery as not being only about controlling symptoms, but also about living a fulfilling life and regaining a sense of meaning.

Work? For me it's waking up in the morning. Work for me is doing something that you enjoy, because when you enjoy something, no matter how tired you are, you will get up and do it. Lived experience

I don't think he would want to walk away from it, he wouldn't just walk away, he wouldn't just quit because he's not a quitter. He's not lazy or anything, he's not scared of work. It's hard work, he's not scared of work so he wouldn't just quit, the only way he'd stop is if he got sacked. Family Member

For some people with schizophrenia, the decision not to seek employment is related to the loss or feared loss of benefits. This was identified as a barrier in our interviews and it had also impacted on work performance.

Because she was only working part time, I think the Benefits Agency was trying to say that she should be fit enough to work full time, and therefore she would be penalised in her benefits. She was trying to do everything herself, the appeal and going to the actual appeal hearing. When I was having a conversation with her, she said to me "I am in a bit of a tizz because I can't really focus on my work". Employer

The assessment process for disability benefit can also be an extremely stressful experience for people with a severe mental health condition such as schizophrenia. It was identified that some people may not be able to convey the extent of their condition appropriately, especially if under pressure, and that this might have implications for the support they receive.

Because people like my son are going to be hugely disadvantaged by these tests. Because he hasn't got a voice, like many, he has not got a voice to deal with people like that. They interview him, "what can you do, how does your illness affect you?" He's not able to explain and he doesn't think he is ill, so he would say to them "I'm not ill, I'm alright".

Carer

For those who are employed, fear of discrimination has been highlighted as a reason why many people with schizophrenia choose not to disclose their condition. None of the participants with lived experience of schizophrenia had been open about their condition at work.

The benefits of disclosure can include greater access to support and reasonable adjustments to the role and the workplace, which may enable an individual with schizophrenia to remain in work.

Taking a decision not to disclose can be positive as well. It can be seen as affording individuals some control over their condition and what people around them know about them, making them less defined by their condition.

Occasionally it does, I think, give people a sense of actually they have some control in the disclosure, it's as much about catching out the employers as it is about the employers finding out about them.

Vocational Manager

Thinking of it now, it has made me stronger knowing how I can overcome it. Like I've come out of a situation and people look at me and if I never tell them, they won't know.

Lived experience

I knew what she was capable of – Experiences of employing someone with schizophrenia

There is evidence that having contact with people with mental illness can reduce stigmatizing views. Evidence indicates that employers are more aware of the extent of mental illness in their workforce, though awareness and understanding is more limited in terms of less common, more severe and enduring conditions, such as schizophrenia:

I'm not really sure to be honest if my perception has changed, I don't think I really had one before. I think it's just made me more aware. Employer

Those with experience of employing someone with schizophrenia suggested that time taken for providing support is a bigger issue for them than direct financial costs. In our interviews, it was considered that the experience of employing someone with schizophrenia may put some employers off employing someone in the future, given that it can take some time and effort to manage.

He has taken up an awful lot of management time because he has had a number of episodes that we've had to manage and we've had to put an awful lot of adjustments in place. Employer

There is also evidence that a supportive work environment enables people with mental health conditions to remain in work by making them feel that their needs are accepted and that they can ask for help and support when it is needed. Support may just be ensuring there is someone to talk to when they become stressed and that reasonable adjustments are put in place, such as flexible working times and rearranging workstations. It is important that clear pathways to support are in place so it is easy to see that further support is available and how it can be accessed.

The importance of having a supportive line manager, or someone in work with whom an employee knows they can talk to, was emphasised as crucial through all the employer interviews. In fact, a good line manager can be seen as a reasonable adjustment itself.

I would say that you need to have the right manager only because of the nature of the condition, they are obviously quite paranoid. They feel that they don't trust very easily. Having a manager that is open with them and able to meet with them regularly and have honest conversations, I think that's imperative to the relationship. Employer

For an employer who has never previously worked with someone with a severe mental illness such as schizophrenia, support, training and advice on how best to manage the condition in the workplace is important. The employers we interviewed said they lacked information on what to do in difficult situations, and had not been aware of where to access support, for example in terms of what reasonable adjustments might be necessary.

I think employers need help as well, and maybe sometimes employers don't feel like they can ask for help, because they are made to feel like they are the experts and they should know how to deal with employees. Employer

The burden cannot just fall on employers however, and other sources of support are equally important. Access to specialist support, such as occupational health or members of the individual's healthcare team, was highlighted as particularly helpful.

So to have advice at work, occupational health people that will be available, there and then, when you need to deal with a situation. I think that would be really helpful. Lived experience

We don't really have any specialists that can help us with giving us more informed information. So for the individual that I mentioned, he did have a specific consultant who was a specialist in that area and so he did give us an extremely detailed report and answered all of our questions, which was extremely useful. Employer

Employers emphasised that it is a two way process and that an employee must also take some responsibility for themselves. This might include continuing to take their medication, engaging with their healthcare team, and being as open as possible about their condition to allow employers to respond to their needs.

There was a responsibility taken on both sides so it wasn't just about what we can do for him but what he can do to help himself as well. Employer

With the right support in place, employers found that employees with schizophrenia could be as good an employee as anyone else.

He's extremely able. When he is calm and he's taking all his medication and everything is right for him, he's extremely able. I wouldn't say he's a top performer but he's certainly not an under performer either. Employer

I could see she had potential. I saw that she had all the required criteria, I am on [the] appointment panel, so I knew what she was capable of. Employer

What interventions are needed?

There is an array of interventions available to support people living with schizophrenia wishing to play a more active part in the labour market. These interventions are strongly supported by evaluative evidence. In the right circumstances, and delivered effectively, psychosocial interventions, pharmaceutical interventions, Individual Placement and Support (IPS) vocational interventions and other community mental health interventions can all be relied upon to deliver improved clinical and employment outcomes in many

cases. There is, however, a huge gap between our knowledge and practice. In our research, we identified several reasons why these interventions have been, and continue to be poorly implemented:

- **Individual differences.** Schizophrenia affects every individual differently. Illness-related factors, such as the onset and type of symptoms, the timing of the diagnosis, and co-morbidities, and social factors such as capability for self-management and available support networks, all vary by each case. Because no one with schizophrenia is the same, it is challenging to develop an employment support service strategy that would work for all.
- **Attitudes and expectations.** Many people with schizophrenia are very motivated to work, but expectations about employment among stakeholders vary greatly. Even though the majority of experts we interviewed were generally positive about work, many people have low expectations about how well someone with schizophrenia would be able to adapt to long-term, competitive employment, and often it is not seen as an achievable outcome. The stigma of others, often leads to self-stigma, impacting on their initial motivation.
- **Timeliness of interventions.** Because employment rates among people with schizophrenia are so low, efforts tend to focus on getting those who are unemployed into work, rather than supporting those already in education or employment to remain. With more timely interventions it should be possible for those young people with schizophrenia still in education to manage the transition to the world of work and for those people who receive a diagnosis while in a job to stand a better chance of retaining it.

What stakeholders can do to support people with schizophrenia into employment?

Government

- **Reaffirm employment as an outcome.** Updating the Commissioning Outcomes Framework (COF) to include employment as an outcome, is essential as it enables Primary Care to support job retention and the return to work of people with chronic conditions from the earliest stages. That would also allow more rigorous data collection on the employment status of people with severe mental health conditions. The data would make it possible to critically evaluate the effectiveness of current interventions aiming to improve return to work and job retention.

- **Implementation of the Health and Work Assessment and Advisory Service.** Implementation of the service, as set out in the government's response to the Sickness Absence Review, is important to ensure that people in danger of slipping out of the labour market as a result of serious mental illness receive both clinical and vocational support in a timely manner.
- **Expand the focus of the government's response to the Independent Review of Sickness Absence to include severe mental health.** Whilst we welcome the focus on common mental health conditions (such as anxiety and depression) and employment in the government's response to the Review, particularly the promise to 'include more support for GP education on mental health and employment', we feel that this should be expanded to include severe mental health conditions where appropriate.
- **Review of the Work Capability Assessment (WCA).** It is necessary to make adaptations to the WCA to make it more sensitive to the functional capacity fluctuations experienced by people with schizophrenia and other severe mental health conditions.
- **Development of a national plan to increase employment rates of people with severe mental health conditions.** It is essential that the Government establishes a task force of multi-disciplinary experts, chaired by Ministers from both the Department of Health and the Department of Work and Pensions to design a plan for the UK to increase employment rates among people with schizophrenia to 25 per cent within a decade.

Healthcare professionals

- **Ask patients about their work history and their employment aspirations at the earliest opportunity.** For some people with schizophrenia work is important and may be a realistic outcome. It may also have therapeutic benefits. Employment should be taken into consideration when making decisions about treatment.

- **Seek early advice from employment support specialists.** They can advise on pathways back to employment and reinforce clinical interventions. An approach based on the notion that symptoms must be stable before employment can be considered, may not always be the case.
- **Focus on capacity, not incapacity.** Schizophrenia is undoubtedly a serious illness, but it is important to emphasise what someone living with the condition can still do rather than what they can't due to their functional impairments. If we are to encourage self-management, increase social inclusion and facilitate a return to paid employment, a positive attitude is important both with people with schizophrenia and with their families and carers.
- **GPs and Community Mental Health Teams** need to have more information on the relationship between severe mental illness and employment. The evidence base for supported employment and other interventions should be made more accessible to those in the 'front line' of care to avoid the persistence of negative views about employment influencing the care and advice given to those living with schizophrenia. Multi-disciplinary education and training for healthcare professionals should be available to avoid 'siloed' thinking.
- **Increase, rather than reduce, investment in Early Intervention in Psychosis Services.** The service plays a significant part in helping to prevent relapse . This, in turn, enables people living with schizophrenia to re-engage successfully with activities of daily living, their education and even with employment.
- **Peer support workers** should be part of every Community Mental Health Team and Early Intervention team. The evidence shows they are valued by service users and can support self-management and return to work.

Employers

- **Seek information on severe mental health conditions and how they can be managed in work.** Ensure that you are sufficiently well-informed and prepared to respond if an employee discloses that they have a serious mental illness such as schizophrenia. This may be by having access to occupational health expertise or by seeking professional support from a patient advocacy organisation (such as Rethink Mental Illness or MIND), from a local NHS provider or from a private health insurer.

- **Develop an open, friendly work environment to enhance disclosure.** Many people with schizophrenia decide not to disclose their condition to their boss or their co-workers because of the ignorance and stigma surrounding schizophrenia in wider society. If your organisation's culture makes disclosure unlikely or impossible it is less likely that an employee with schizophrenia will be able to access the support they need. This will lead to a greater impact on your business.
- **Be prepared to make adjustments at work to accommodate the needs of people with schizophrenia.** In most cases these adjustments will relate to working time. Often they can be constructed in conjunction with the employee, who will – perhaps with input from an employment support worker or clinician – be able to indicate which working patterns or job responsibilities need to be adapted to allow them to remain productive at work.

Families and carers

- **Get access to support.** It can be easy to feel that you are alone against the system but this should never be the case. There are many organisations that can help you to navigate your way through the services that offer support to people with schizophrenia and their families. Some of these can be accessed through GPs and other healthcare professionals and others through patient advocacy organisations, charities and employment support organisations.
- **Support their aspirations and goals.** It is important that you and the person you care for have shared goals around how you can support them in their aspirations. It may be about finishing off a course of study, getting or keeping a job, living independently or pursuing a creative interest. Whatever it is, it will be easier to achieve if you work together.

People with schizophrenia

- **Help yourself to keep well.** Getting to know yourself and the events or feelings which might trigger your illness is an important aspect of self-awareness and self-management. Everyone is different, but keeping well by identifying what keeps you on an even keel and doing more of it can help you succeed in getting and keeping work. Part of this process is to focus on your talents and strengths rather than on your illness and how it might sometimes limit you.

- **Make sure that your employment aspirations are heard by your healthcare team.** Even if the priority right now is to establish the most appropriate treatment for you and to help you to manage your own health, there is likely to be a point at which work becomes something you aspire to. There is plenty of support available to help you and your family, and you should certainly seek advice from an employment support specialist who will be able to help you think through your options.
- **Try to choose appropriate work.** If you know that dealing with customers stresses you out, then this type of work may not be for you. But if there is a job or career you strongly desire, make sure you have got supports in place to help you pursue it and to deal with any setbacks along the way. Also, remember your job interests can be reflected in things you do outside work – you can get support to try out work that interests you or which relates to a special talent or hobby. This also can be a stepping stone to your goals – don't lose sight of them.
- **Stay positive.** The job market is tough at the moment, but our research has uncovered many great examples of people with schizophrenia in long-term, meaningful employment. Do not let your condition control your life – there are many options and support available to help you to manage your illness and move forward with your life.

2 Introduction

Approximately 450 million people worldwide are living with a mental health condition that impacts on their ability to perform activities of daily life, including their capacity to maintain employment (World Health Organization, 2001). It is estimated that one in four people in the UK will experience some type of mental health issue in the course of one year¹. Many individuals with a mental health condition are forced to take temporary time away from the workplace, putting them at risk of not being able to retain their jobs. At the same time, for those who are in education or not employed, and particularly those who are long-term unemployed, mental health conditions may act as a barrier which impedes entry into the labour market and may hamper their future career prospects.

Difficulties in relation to work are exacerbated for those with more severe mental health conditions, such as schizophrenia. UK employment rates for people with schizophrenia are estimated to be between 5 per cent and 15 per cent, with the average rate of only 8 per cent. This is in stark contrast to a UK-wide working age employment rate of 71 per cent (as at Dec 2012). More than just being desirable, work is considered to have many advantages for people with schizophrenia, not only in terms of financial gain, but also providing a stabilising or normalising influence with improved general and mental health and wellbeing (Haro et al., 2011; Waddell & Burton, 2006).

Even though a considerable proportion of working age people with a history of schizophrenia are able and willing to work, and repeatedly express the need for job training, placement and support services (Macias, DeCarlo, Wang, Frey, & Barreira, 2001), this group encounters one of the highest unemployment rates among all vocationally disadvantaged groups (Kilian & Becker, 2007). Studies highlight that very low employment rates are not intrinsic to schizophrenia, but reflect the interplay between the social and economic pressures faced by the individuals, the labour market and psychological and social barriers to working, including stigma (Marwaha & Johnson, 2004).

The traditional approach to managing schizophrenia has focused primarily on managing the clinical symptoms of the condition and with the aim of attaining clinical recovery, often without considering individuals' needs and aspirations for employment as a treatment target (Schultz & Rogers, 2011). Yet there is convincing evidence highlighting what the barriers to working are for people with schizophrenia, and what can be done to address them. Given the evidence base and the consensus on the topic, it is disappointing that our knowledge of 'what works' has still not been translated into mainstream policy and practice in the UK.

1 <http://www.mentalhealth.org.uk/help-information/mental-health-statistics>

Much of the discourse regarding the employment of people with schizophrenia is rightly from the perspective of the needs of individuals living with the illness. It is also important, however, to consider the perspective of the employers, and the perceived and actual barriers which may be preventing them from employing people with schizophrenia. By making it easier for employers both to employ people with schizophrenia and to provide them with the support they need to stay in work, then employers will be more likely to see and value the skills and experience of the individual employee, which are often obscured by their diagnosis.

This report seeks to provide a summary of the existing evidence about the benefits, barriers and interventions which can help those with schizophrenia to obtain and maintain employment. Adding to the existing evidence base are the outcomes of interviews with people with expertise on schizophrenia and employment, including a range of healthcare professionals, carers and those in employment support services. Most importantly, the views and experiences of people living with schizophrenia seeking and trying to maintain employment are featured.

This report also takes a supply and demand approach – looking not only at how to make changes for workers, but also considering employers side – what needs to be done to enable and encourage them to employ and retain people with schizophrenia.

Finally, the report aims to identify gaps in service provision and makes recommendations about how to move forward, with the aim of breaking down the barriers to work and a normal life experienced by so many people with a diagnosis of schizophrenia.

2.1 Objectives

We have conducted this research to examine the impact of schizophrenia on employment, with a particular focus on the individual, attitudinal and structural barriers faced by people with schizophrenia and also to examine interventions that help people to stay at work or enter into work life. Keeping these broad objectives in mind, this report aims to answer the following research questions:

- What are the barriers to employment and remaining in work for people living with schizophrenia?
- What are the most important factors that influence the ability to work or remain in work for people with schizophrenia?
- What are the employer's views of hiring and working with someone with schizophrenia?

- What interventions help people with schizophrenia enter or remain in employment?
- What can policy makers and key stakeholders do to reduce the barriers to employment for people with schizophrenia?

We have further made policy recommendations on how to best increase the number of people with schizophrenia who are active in the labour market. We have directed our messages to different stakeholders, in particular to healthcare professionals, employers and caregivers to advise how they can better support people with schizophrenia at work, as well as considering what people with schizophrenia may be able to do for themselves.

2.2 Methods

To answer these research questions, we conducted a literature review including recent policy reports in the area of mental health and those that have looked at the work situation of people with schizophrenia. In addition, we reviewed the clinical, economic and labour market literature published in peer-reviewed scientific journals.

To supplement and add a further practical evidence base to results of the review, we conducted a number of telephone interviews with experts (Appendix 1). Subject matter experts included healthcare professionals, as well as experts from patient groups, employers, occupational health specialists, employment support workers, caregivers, friends and family members.

Depending on the subject knowledge of each expert, the interviews focused on a range of clinical, occupational health and labour market issues. Among other things, we gathered their views on the labour market benefits of changes to current early diagnosis and intervention practices, and to identify innovative policy and practice in the UK.

In order to gain an in-depth understanding of how the structural, economic, clinical and attitudinal barriers impact people with schizophrenia, we conducted five in-depth interviews with people with lived experience (Appendix 2). The aim of the case studies was to conduct an in-depth exploration of the experiences of people with schizophrenia in relation to the labour market, and examine what role and impact employers, employment support workers, healthcare professionals, caregivers and families or close friends have in the working lives of these individuals, with a particular focus on labour market barriers.

A thematic analysis methodology was used to identify commonality and difference in the participants' experience. This method is particularly suitable for analysing semi-structured interviews that aim to identify themes and patterns of experiences and behaviour (Lindlof & Taylor, 2002). Participants were encouraged to express their personal views and experiences in each theme. The interviews were recorded and transcribed as verbatim. Each interview took 30 to 90 minutes.

2.3 Structure of the Report

The remainder of this report examines:

- **Chapter 3** The impact of schizophrenia – focusing on the clinical aspects of the illness, its labour market consequences, societal impact and the perspective of employers;
- **Chapter 4** Interventions – highlighting the range of interventions which can support both recovery and access to work for people living with schizophrenia;
- **Chapter 5** Conclusions and recommendations – with targeted suggestions for actions which each stakeholder group should prioritise if we wish to increase employment rates among people living with schizophrenia.

3 What is the impact of schizophrenia?

3.1. Schizophrenia as a clinical and social condition

Schizophrenia is a severe form of mental illness. The consequences of having schizophrenia are associated with significant and long-lasting health, social, and financial burdens, not only for patients but also for families, other caregivers, the healthcare system and social services. The condition affects around 1 per cent of the UK population (National Institute for Health and Clinical Excellence, 2009) with roughly equal numbers of men and women affected (McManus, Meltzer, Brugha, Bebbington, & Jenkins, 2009; Papageorgiou, Cañas, Zink, & Rossi, 2011). In the UK, increased incidence of schizophrenia has been consistently found among individuals of African-Caribbean and African origin and less consistently in those of South Asian origin (Boydell et al., 2001). Most commonly, the onset of schizophrenia occurs at the threshold of adulthood (McManus et al., 2009) – when young men and women in their teens and 20s are likely to be making the transition to independent living. For this reason, the onset of schizophrenia will likely have considerable implications throughout someone's life which can include physical illnesses, lost or damaged relationships, academic failure, unemployment, dependency, isolation, imprisonment and homelessness (NAMI, 2008).

People with schizophrenia die 15-20 years earlier than the general population (The Schizophrenia Commission, 2012). A study looking at the mortality gap for people discharged from inpatient care with schizophrenia and bipolar, against the general population in the UK (between 1999 and 2006) found that mortality ratios were double the population average (Hoang, Stewart, & Goldacre, 2011) causing more loss of lives than most cancers and physical illnesses (van Os & Kapur, 2009).

The illness itself, its treatment, and modifiable lifestyle factors all contribute to the excess morbidity and mortality. Though suicide is clearly an important factor, research indicating that the suicide rate among people with schizophrenia is between 5 and 13 per cent (Pompili et al., 2007), the National Audit on Schizophrenia (Royal College of Psychiatrists, 2012) highlights the considerable impact of cardiovascular disease and diabetes on the life expectancy of people with schizophrenia. This is attributed in a large part to modifiable risk factors, including smoking and obesity, caused by poor diet and low physical activity. Weight gain is also a side effect of many antipsychotic medications (Connolly & Kelly, 2005). Low rates of monitoring of risk factors by healthcare providers is thought to compound this issue (Royal College of Psychiatrists, 2012).

There is also a higher likelihood of illicit drug use, especially stimulants and cannabis, among people with schizophrenia compared to the general population (The Schizophrenia Commission, 2012). Both illicit drug use and smoking have been linked

to worse health and social outcomes – including more persistent symptoms, repeated hospital admissions, and more aggressive behaviour (The Schizophrenia Commission, 2012).

Because many people with schizophrenia have several relapses, it contributes to multiple hospital stays and is the eighth leading cause of disability worldwide among 15-44 years olds. In developed countries, the direct costs of schizophrenia are around 1.3 per cent and 2.5 per cent of total health expenditure, depending on the country. These costs represent the highest proportion of total costs for mental illnesses (Andrews, Knapp, McCrone, Parsonage, & Trachtenberg, 2012). According to recent figures, the total societal costs in England are estimated at £11.8 billion per year and the cost to the public sector of £36,000 per person with schizophrenia (Andrews et al., 2012).

Symptoms and progression

There is no single symptom picture that is unique to schizophrenia. This reality complicates the definition of the condition. Instead, the diagnosis is given on the evidence of a variety of experiences and behaviours felt by an individual, which are believed to be typical of schizophrenia.

Schizophrenia is a type of psychosis. Psychosis can be defined as a loss of contact with reality, often involving delusions and hallucinations². Symptoms seen as characteristic of schizophrenia are often grouped as ‘positive’ or ‘negative symptoms’, with some definitions also distinguishing cognitive symptoms. The progression of schizophrenia is generally seen as occurring in three phases: 1) The prodromal phase, often characterized as a deterioration in function which cannot be identified as schizophrenia until the next stage occurs; 2) the acute phase, when psychotic (positive) symptoms are experienced; and, 3) the residual stage, where psychotic symptoms have abated but negative (and cognitive) symptoms continue. To be diagnosed with schizophrenia, an individual must have experienced more than one psychotic episode, along with other, non-typical symptoms, such as depression, problems with concentration, attention, energy, emotional or social withdrawal or self-neglect.

The presence of one or more positive symptoms (sometimes referred to as psychotic symptoms or experiences) characterise the ‘acute’ (or active) phase of schizophrenia³. These include:

- Delusions (apparent exaggerations or distortions of thinking);

2 <http://www.nlm.nih.gov/medlineplus/ency/article/001553.htm>

3 <http://www.health.am/psy/more/stages-of-schizophrenia/>

- Hallucinations (auditory, sensory and/or visual);
- Disorganized speech - as a manifestation of thought disorder (dysfunctional, disorganised ways of thinking that can make speech difficult);
- Grossly disorganized behaviour (e.g. dressing inappropriately, crying frequently, impulsivity) or catatonic behaviour.

Negative and cognitive symptoms may develop before the onset of, or continue in the absence of positive symptoms (at the prodromal and residual phases), and appear to be more long lasting and persistent than positive symptoms. These symptoms represent an apparent loss or diminution of normal functioning or withdrawal that can often impact on social aspects of life such as the relationship with family and friends (Blanchard, Kring, Horan, & Gur, 2011). As such they have been identified as particularly important in terms of ability to work.

Negative symptoms seen as characteristic of schizophrenia can include⁴:

- Lack of emotion - the inability to enjoy regular activities (socialising with friends, etc.) as much as before;
- Low energy - the person tends to sit around and sleep much more than normal;
- Lack of interest in life, low motivation;
- Affective flattening - a blank, blunted facial expression or less lively facial movements, flat voice (lack of normal intonations and variance) or physical movements;
- Alogia (difficulty or inability to speak);
- Inappropriate social skills or lack of interest or ability to socialize with other people;
- Inability to make friends or keep friends, or not caring to have friends;
- Social isolation - person spends most of the day alone or only with close family.

Evidence suggests that people with lived experience of schizophrenia have different levels of insight or awareness of their own illness, and that this may vary across time. It has been suggested that the consequences of poor insight in schizophrenia are broad and can include non-compliance with medication, increased risk of relapse, increased

4 <http://www.schizophrenia.com/diag.php#common>

hospitalisations, impaired psychosocial functioning and poorer prognosis. However, insight can be enhanced through a number of therapies as motivational interviewing and cognitive behavioural therapy (Turkington, Dudley, Warman, & Beck, 2006).

Following resolution of the acute episode, usually after pharmacological, psychological and other interventions, symptoms may diminish or entirely disappear for many people. Between 21 and 30 per cent of patients treated for a first psychotic episode have no symptom relapses over 5 years (Mueser & McGurk, 2004). This is increased when interventions occur earlier.

Road to recovery

[Recovery is] *“a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness...”* (Anthony, 1993)

Although chronic, schizophrenia today is a manageable condition. Advances in treatment and support, including antipsychotic medication, psychosocial therapy, and rehabilitation, now enable many people with schizophrenia to recover and live productive and fulfilling lives (National Institute for Health and Clinical Excellence, 2010).

There are different ways in which recovery from mental illness is defined. Rethink Mental Illness⁵ distinguish between “clinical recovery” – a medical concept that includes removing symptoms, regaining social functioning and enabling people to “get back to normal” – and “personal recovery” which is a concept that has come from people with lived experience. In recent years there has been growing interest in the idea of recovery from mental illness, not in the sense of clinical cure but rather in being able to lead a meaningful and satisfying life, despite symptoms and problems. This interest has led people to define recovery, how it translates into practice and the implications for healthcare professionals, service delivery, family members and service-users (G. Shepherd, Boardman, & Slade, 2008).

Similarly, two London-based mental health trusts have also looked at the implications of taking a recovery-oriented approach to psychiatry and in their report, “Recovery is for All” (South London and Maudsley NHS Foundation Trust & South West London and St George’s Mental Health NHS Trust, 2010), they define recovery as a process and identify three main concepts:

5 http://www.rethink.org/living_with_mental_illness/what_is_recovery/?shortcut=recovery

- **Hope.** *Hope is a central aspect of recovery as recovery is probably impossible without hope. It is essential to sustaining motivation and supporting expectations of an individually fulfilled life.*
- **Agency.** *This refers to people gaining a sense of control. Recovery means service users taking control over their own problems, the services they receive, and their lives. It is concerned with self-management, self-determination, choice and responsibility.*
- **Opportunity.** *This links recovery with social inclusion and thus peoples' participation in a wider society. People with mental health problems wish to be part of communities; to be a valued member of and contribute to those communities; and have access to the opportunities that exist within those communities.*

All three of these concepts of recovery are important in contributing to the journey towards work – a key indicator for a lot of people with schizophrenia that they have “recovered”.

The link between paid work and recovery, it's very high on the agenda for mental health service users to get a job, to keep the job that they have. Vocational Manager

3.2. Impact of schizophrenia on employment and the importance of work

Despite expressing the need for job training, placement and support services (Macias et al., 2001), this group encounters one of the highest unemployment rates among all vocationally disadvantaged groups (Kilian & Becker, 2007). A large international study combining data from 37 different countries found that on average, 19 per cent of people diagnosed with schizophrenia were in paid employment, with figures ranging from 16.2 per cent to 22.6 per cent, against an average employment rate in the general population of 75 per cent and 80 per cent (Haro et al., 2011). The 2012 report of the Schizophrenia Commission reported a much lower employment rate in the UK, an average of 8 per cent with the range of 5 per cent - 15 per cent.

The very low employment rates seen for people with schizophrenia are not intrinsic to having the condition. Studies show that most individuals with severe mental illness face a range of barriers in gaining employment (Gioia, 2005; Marwaha & Johnson, 2004; World Health Organization, 2001). Marwaha and Johnson (2004) conclude that low employment rates are heavily influenced by the social and economic pressures faced by the individuals, the reality of the labour market, and psychological and social barriers to working.

The most obvious barrier impacting of people with schizophrenia's ability to work are the symptoms of the condition. In our interviews, experts identified negative and cognitive symptoms as being most problematic in terms of work, highlighting difficulties with interpersonal relationships, difficulties with executive function or cognitive impairments, particularly processing and learning new tasks. This is in contrast to the more common assumption that it is positive or psychotic symptoms which impact on working ability. Despite the rare nature of these symptoms, it is these which are often seen as a cause for concern.

A lot of people with schizophrenia for example, will tend to manage their symptoms by withdrawing because they find it easier to be on their own. It's a less intense environment for them and that's often how they manage psychosis, by withdrawal. Psychiatrist

It should also be noted though that some people with very severe conditions and co-morbidities, may not be able to work. The variation in symptoms and severity of symptoms seen across the spectrum of those diagnosed with schizophrenia, mean that some people with schizophrenia cannot work, and that work should not be an outcome for all people with schizophrenia as currently defined. These people will need to be supported in different ways to have an improved quality of life.

I know and accept that a lot of people with severe mental illness get better and they recover enough to go out and get work. But some, like my son, that's got really complex illnesses, they can't and they never will. I think society and the government need to recognise this and support them to get the care they need to help them have a decent life so they're not just holed up in flats doing nothing. Carer

Even though for some individuals with severe forms of schizophrenia, work may not be realistic outcome, it is generally is considered to have many advantages, not only in terms of financial gain, but also in addressing social inclusion and assisting their mental health and wellbeing (Marwaha & Johnson, 2004; Waddell & Burton, 2006). There is some evidence that many working age people with a history of schizophrenia are able and willing to work, with one study suggesting as high as 70 per cent (Macias et al., 2001) would like to work. . Further to this, some UK research evidence suggest between 30 and 50 per cent of people living with schizophrenia are capable of working (Marwaha & Johnson, 2004).

Our evidence is that a small, and I don't think it's a majority at all, that a small but significant minority with schizophrenia are very keen to return to work. Academic Psychiatrist

The evidence of the beneficial nature of work for people with schizophrenia (Bell, Fiszdon, Greig, & Bryson, 2005; Bell, Lysaker, & Milstein, 1996; Bryson, Lysaker, & Bell, 2002) was reaffirmed in our interviews. These included: increasing social skills and enhancing the opportunity for the development of friendships, learning new skills, financial rewards, and stabilisation of condition. The most frequently highlighted benefits were the positive impact of work on individual's self-esteem, and providing a structure to the day.

Apart from medication which is necessary for my daughter, to make her normal and keep her alive, second to that, hugely important, is work. Family member/Carer

In general, people we interviewed with lived experience of schizophrenia were really motivated to work. In addition to having a job to provide a sense of normality and financial gains, the importance of having a job that they enjoyed was highlighted – for some this was seen as incredibly valuable to their health.

Work? For me it's waking up in the morning. Work for me is doing something that you enjoy, because when you enjoy something, no matter how tired you are, you will get up and do it. Lived experience

I think I feel a lot better when I am working because, I've been working at a bakery and even though I'm really bad at it, he said I'm on my last chance, basically when I'm working there I do feel better. Even though it doesn't seem like, he doesn't know anything about my mental health problems. But I do make a lot of mistakes and I'm distracted by my intrusive thoughts. But I'm still better there than I would be if I was at home. Lived experience

My health was a lot better then, it was a lot better, because I was doing a job that I was enjoying, obviously my health had improved. Lived experience

This reflects the concept of recovery as not being only about symptoms, but also about living a fulfilling life and regaining a sense of meaning (G. Shepherd et al., 2008). In this sense, recovery can be seen more as a means to the end of facilitating the achievement of life goals, including employment.

Today work means a means to get your bills paid and independence. Lived experience

Independence from family, financial help like benefits and things like that. Lived experience

Many people have received the interventions for a long time and they are still in the service, but their life hasn't improved too much. Some may have less symptoms while some feel worse than at the beginning of treatment. But people's aspirations are: to have a girlfriend, a job, a new house. They don't say "I want less symptoms".
Occupational therapist

I'm sure if she starts working, she starts getting her life back and her confidence and self-esteem again, everything is going to be OK. Family member

Doing a job that you enjoy is even more beneficial, in terms of recovery and wellbeing, and in terms of being able to remain motivated and retain a job.

I am in employment but I mean it's sometimes, the stress is there but it's not doing the type of job that I'd like to be doing, so that upsets me a great deal. At the same time you could say to yourself you're lucky to be in employment. I would like to be doing something I enjoy. Lived experience

The distinction between voluntary and paid competitive employment is also important. For example in the case of one participant, who had the enormous set back of having to return to voluntary activities after being told that he was not felt to be able to do a full-time job after working there on a placement.

I was very upset and obviously it affected my mental state and I continued with the medication, but more so now. I think it was quite a terrible time. Lived experience

3.3 Individual barriers to employment

I think also what has been challenging [are] the myths that persist about mental health and employment. Myths that are broadened in a job centre and myths that are broad at a policy level and myths that are broad within mental health services. People with severe mental health illness don't want to work, they can't work, they won't work, it's too stressful for them to work, they need to this, that or the other to work. They need to do pre-potential training to work, all the myths, it's about challenging all of those myths I think and cutting to the chase and saying look there's somebody out of work and they want a job. Vocational Manager

The barriers to employment for people with schizophrenia are well-documented and comprise of a combination of individual, attitudinal and structural factors. Individual factors include such things as low self-esteem, low expectations and lack of motivation. Attitudinal factors include stigmatisation and can further reinforce, and create a

cycle of, low expectations among people with schizophrenia. For example, some healthcare professionals underestimate the capabilities, skills and experience of their clients, which in turn fuels their clients' own doubts and fears, leading to self-stigma. Stigmatisation, real or perceived, is commonly cited as one of the biggest barriers to employment for people with schizophrenia. Structural factors, such as financial disincentive and fear of losing benefits, are also recognised as a common barrier.

Studies show that mental illness is seen by employers as affecting cognitive capacity, decision-making ability and the capacity to deal with stress and pressure, possibly leading to dangerous behaviour (Baron & Salzer, 2002; Wahl, 1999). As a consequence, employers believed that persons with schizophrenia could only perform low-level, low-skill, and repetitive manual labour roles.

Poorly informed employers with limited knowledge, experience, or access to support on how to assist and maintain an employee with schizophrenia make it difficult to employ and retain them.

Barriers can also be seen in a broader context. Economic conditions and the condition of the labour market can provide a barrier – in times of recession and high unemployment, finding work is more difficult in general, and likely more so for those with less concrete work history or lower levels of education. Poor access to quality vocational rehabilitation and support services means that help to find work is also often lacking.

“The key barrier” – Stigma and discrimination

I think there's a lot of stigma and damage associated with receiving a diagnosis of schizophrenia. Psychological Therapist

Despite evidence of the benefits of employment for people with schizophrenia, a keenness of people with schizophrenia to work, and the development of interventions which address the impact of symptoms, this population remains severely underrepresented in the workforce. Arguably, the most prominent non-clinical reason for this is the considerable stigma people with severe mental health conditions experience in society.

It was really a taboo; we wouldn't talk about people with mental health when I was younger because it's such a scary thing to talk about. And I remember back home, there was this guy who was mentally ill and I remember him running naked outside where we were playing and we thought oh gosh, he is coming, let's run away. We were always fearful of people with mental health [conditions]. Lived experience

Stigma consists of three components: (i) ignorance (lack of knowledge, information); (ii) prejudice (negative emotional reactions); and (iii) discriminatory behaviour (Thornicroft, 2006). There is a body of evidence indicating that people with schizophrenia are affected by stigma in multiple areas of their lives, and especially in employment (Schulze & Angermeyer, 2003; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). Employees with a mental health condition have reported discrimination from previously supportive colleagues and managers upon returning to their job after a period of illness. This may take the form of critical or negative remarks, mistrust and denial of previously proven skills (Schulze & Angermeyer, 2003; Stuart, 2006).

There is a general belief that "people with schizophrenia are not able to do things very well" that "they will fail". Psychologist

Low expectations of society, as well as of people who are close to them, are strong barriers to employment for people with schizophrenia. Family is highlighted as impacting on individual perception of themselves as able to work. Our interviews showed concerns about the impact of work on wellbeing, highlighting they were concerned about the potential for relapse when faced with stress, workplace bullying, and poor support systems.

My husband kept saying this is the kind of job that she cannot have, it's too much in your mind, you cannot have stress because you cannot be exposed to stress. Carer/
Family member

Even though healthcare professionals often claim that they believe that people with severe mental health conditions can work, when they are asked about the capacity of their own clients, they are less likely to see work, particularly paid work, as a possibility (Marwaha, Balachandra, & Johnson, 2009). Thus it is likely that mental healthcare professionals are no less susceptible to stigmatizing beliefs than the general population (Ping Tsao, Tummala, & Roberts, 2008). Among healthcare professionals, barriers to employment are their low expectations, a low appreciation of the importance of work as a desirable outcome, and concerns for individual wellbeing (Marwaha et al., 2009).

I think there's a workforce in mental health that doesn't have an expectation for people that they could get back into work. And that's not out of badness I don't think. I sometimes think that mental health staff feel that it would be an unkind thing to do, to try and get somebody back into work, to force them into work. And that's definitely not what I'm talking about; this is about supporting the person to function as they can and with what they want to do. Nurse Consultant

I don't think the difficulties, the challenges, necessarily have ever been with service users, they see it much more clearly than some mental health professionals. It's been about raising awareness and raising aspirations within the mental health teams and with individual workers around paid work. Vocational Manager

Concerns among healthcare professionals may come from their view of continuing symptoms as a sign that a patient is not ready for work that they must disappear before the person is 'ready' for vocational rehabilitation whereas in reality, the symptoms may be manageable in the work environment (Shepherd, Lockett, Bacon, & Grove, 2012).

I think it can work, if people with psychosis have difficulties in coping with stress. And that can exacerbate psychotic symptoms. Psychological Therapist

I think it was a broad view within secondary mental healthcare that work was just not a realistic possibility for people with severe mental health needs. And I think there was a fear, that really I don't think has any support within the research, that as people went into work they would find it far too stressful and immediately become unwell. I think all the research points to quite the opposite, that it's actually likely to be an extremely protective factor in terms of people's mental health. Vocational Manager

That's not withstanding the fact that people do experience distress in the context of the work, but it's much rarer than people think, and it often can be remediated fairly easily with appropriate support and appropriate employment support. Vocational Manager

The views from healthcare professionals we interviewed, however, were more reflective of the evidence from Marwaha, Balachandra and Johnson (2009) which found that there was considerable belief among clinicians of the abilities of people with psychosis to enter some form of work, with some indicating that this might, however, mean non-competitive work (i.e. voluntary or sheltered).

Motivation to work has been identified as a key predictor of employment for people with severe mental illness (Drake, Becker, Clark, & Mueser, 1999) and self-stigma may have a considerable effect on an individual's motivation to work. Respondents to a survey of people associated with the charity MIND, found that 34 per cent of respondents had been forced to resign or dismissed from work and 69 per cent had avoided applying for jobs through fears of discrimination. (Reed and Baker 1996, cited in quoted in (Nithsdale, Davies, & Croucher, 2008). In addition, self-stigma may cause people to avoid accessing

and using evidence-based practices that help achieve their employment (and other) goals. The effects of self-stigma and the “why try” effect can be diminished by services that promote consumer control (Corrigan, Larson, & Rusch, 2009).

A culture of low aspirations is inimical to the paid work aspirations of the service users. It probably becomes one of the key barriers. Vocational Manager

Self stigma comes from societal stigma. I don't think you can separate the two. If society didn't look down on it, they wouldn't look down on it. Psychologist

A European study looking at self-stigma and recovery found over 40 per cent of participants reporting moderate to high levels of self-stigma, and almost 70 per cent reported moderate to high perceived discrimination (Brohan, Elgie, Sartorius, & Thornicroft, 2010). A cross-sectional study with people with schizophrenia across 27 countries found that 64 per cent anticipated discrimination when applying for work, training or education. More tellingly, over a third of participants anticipated discrimination in job seeking when none had been experienced (Thornicroft et al., 2009). The effects of self-stigma were brought up at the interviews with experts and people with lived experience

I've come across people who have low expectations of themselves because they've been told “you'll never work” or “you're going to have a life of taking medication and you're not going to be able to live life to the full”. So I think there are low expectations on people by others as well as by themselves. Psychological Therapist

As a result of the stigma from others, people may be dissuaded from pursuing the kind of opportunities that are fundamental to achieving their life goals because of diminished self-esteem and self-efficacy (Corrigan et al., 2009).

I've got a really negative outlook of work, especially through my experience. Even though you want to work, it is just sometimes the experience of mental health, it just gives you that limitation on what you can handle at work and what you can do and what you cannot do. Lived experience

He's kind of lost a little bit of a spark, but that's just with the knockbacks. Family member

Even without the barriers of stigma, motivation to work can be difficult to maintain given the amount of rejection that someone with schizophrenia is likely to face when seeking employment. What came through in several interviews, however, was the high level of motivation seen in people with schizophrenia in terms of their commitment to getting and staying in, employment.

He's extremely keen to work, he doesn't want to be out of work. He's in his mid to late 40s and we are his first employer and he's only been with us for 5 years. So I wonder if he did struggle to get work before and now obviously, he's extremely keen to keep hold of it, he doesn't want to lose his job. Employer

I don't think he would want to walk away from it, he wouldn't just walk away, he wouldn't just quit because he's not a quitter. He's not lazy or anything, he's not scared of work. It's hard work, he's not scared of work so he wouldn't just quit, the only way he'd stop is if he got sacked. Family member

This is not universal however, and the pressures and experience of the condition make some people lose their motivation.

I was very hard working. But then as time went on, I changed, and it was probably because of my experiences. I'm like oh what's the point if I'm going to fail, or what's the point if I'm going to have mental health and relapse all over again. So that's always in the back of your mind, I'm not that person. I think I can be that person again, but it's very hard to maintain that sort of outlook. Lived experience

An academic expert we interviewed suggested that this difficulty was widespread, and for many schizophrenia has a huge impact on ambition and motivation. The impact of previous negative experiences may also increase fear of working and interacting with others, further de-motivating an individual.

The interviews, however, provided some indication of a general feeling that stigma associated with people with schizophrenia was reducing. Among the general public this can be seen as influenced by a more positive use of language in some broadsheet newspapers and publicity relating to public figures with mental illnesses had had an impact on public perceptions. In terms of healthcare professionals themselves, there have also been signs that attitudes across healthcare teams have changed, especially among the younger generation.

“If I never tell them, they won’t know” – Issues of disclosure

The fear of potential stigma and discrimination in this context plays a very significant role in disclosure decisions. For those people with highly stigmatized conditions such as schizophrenia, disclosing their condition to their current or potential employer may not even feel like an option. This view was prevalent in our interviews with individuals with lived experience: none of them had openly discussed their condition at work.

She was a bit anxious because of her mental health, “they might not take me because I’ve got mental health.” Employment worker

Obviously I don’t think they would have employed me had I told them I was suffering from some form of psychosis. Lived experience

This was the case even in situations where the employer possibly knew that the employee had a mental health condition of some kind, where they had been employed through an IPS Supported Employment agency.

They know that I came from [a supported employment agency], so I think they know, I think they know, but not my specific problem. Lived experience

Some employees with schizophrenia are forced to lie about the nature of medical appointments to prevent their colleagues and managers from finding out about their condition, and leaving themselves open to discrimination, for example, inventing fictional diagnoses such as ‘exhaustion syndrome’ and asking for the help of mental health professional to substantiate their claim (Schulze & Angermeyer, 2003). This problem may be widespread, with 43 per cent of UK adults surveyed by the NHS reporting that they would feel uncomfortable talking to their employer about their mental health (The NHS Information Centre for health and social care, 2011).

Sometimes I tell them, I just tell them I’ve got an appointment, and sometimes I’ll tell them I’ve got an appointment with a therapist... they don’t take any interest, so I don’t think they know where. Lived experience

A literature review on workplace disclosure identified the perceived risks of workplace disclosure as including decreased employment options, being dismissed, laid off or subjected to greater supervision. It was also identified that by not disclosing conditions, employees may miss out on many benefits which might otherwise help them to remain in work, including: improved access to workplace accommodations such as flexible working hours, advocacy to combat stigma, reduction in social isolation, and increased

emotional support from employers and co-workers (Dalgin & Gilbride, 2003). The role of disclosure in gaining greater support from co-workers can particularly become an issue where there is an incident at work or other colleagues witness behaviours that they see as problematic. As noted in one of interviews:

He doesn't want people looking at him in a different way, which is understandable. But unfortunately those people that did publicly witness the incident, they're going to have their own perceptions and not realise that there's a mental health condition. Employer

In interviews with people with lived experience, it was only in the context of a relapse and how that would be seen by employers and colleagues that someone suggested they might disclose their condition.

I'd let them know because I don't want it to be a surprise to them, hopefully it doesn't happen again but if that was to happen, it won't be a surprise, they won't be surprised about it, what's going on with her? And then later on if they find out this, oh she had a background of this and that, it won't be right. So I'll let them know beforehand so they will be aware of whatever could happen. Lived experience

There is evidence to suggest that some individuals may disclose their mental health condition in an effort to explain behaviours that colleagues might otherwise attribute to more stigmatized conditions or behaviour, such as illegal drug use (Brohan et al., 2012). A common problem when conditions are not disclosed is attributing symptoms and medication side-effects to laziness (Lee, Chiu, Tsang, Chui, & Kleinman, 2006).

Just because she [mum] thinks I'm lazy I guess, I don't do it all, but it's not because I'm lazy. So maybe I'm not doing things, but usually it's because I'm anxious, or I'm tired, or I'm not motivated I guess, but laziness I think its more if you have the potential to do something, you don't do it simply because you're not bothered. And I am really bothered about a lot of things. Lived experience

Despite the view across interviewees that disclosure is likely to be beneficial, particularly in terms of ensuring more support and workplace adjustments, there was strong support for the decision to be taken by the individual, based on their level of comfort. This was attributed largely to concerns about negative reaction from employers.

Taking the decision not to disclose was seen by some people with schizophrenia we interviewed as being a positive thing. It can be seen as affording individuals some control over their condition and what people around them know about them.

Thinking of it now, it has made me stronger knowing how I can overcome it. Like I've come out of a situation and people look at me and if I never tell them, they won't know.
Lived experience

Occasionally it does I think give people a sense of actually they have some control in the disclosure, it's as much about catching out the employers as it is about the employers finding out about them. Vocational Manager

We can see the extent of disclosure as a decision about how an individual is defined by their condition. Some have sought to reframe the concept of "disclosure", a word which might suggest some kind of dark secret, in terms of "management of personal information". This seeks to reduce self-stigma, and normalise disclosure by likening it to the same process that any job applicant will go through in deciding what information to divulge at an interview (Waghorn & Spowart, 2010).

[On disclosing their condition to an employer] *Coming to this employment agency, yes, it has opened my eyes to being true to yourself and accepting who you are. Not your condition as a whole, accepting who you are as a person and being honest with your experience. And I think that's more helpful than hiding it.* Lived experience

"Helping to fit the right job to the person" – Types of jobs and work history

A concern often raised in relation to type of work, is whether some roles are more likely to cause harm or even trigger a relapse, by putting an individual in a potentially stressful situation (Krupa, 2004). Consequently there is a tendency for it to be assumed that unskilled, low responsibility roles, with minimal customer contact are the most appropriate job types for people with schizophrenia (Baron, 2000; Krupa, 2004).

People with schizophrenia that participated in the study had various work histories depending on their age, severity of condition and their capability to cope with their illness and as such had taken different roles. All of them had been able to keep jobs for several months, some for several years; the longest time at the same employer was nearly three years. Evidence from our interviews showed that where someone has a poor work history, it may not always be related to their having schizophrenia. Though the reasons for leaving a job identified in our interviews were sometimes related to illness, e.g. a relapse or worsening of the symptoms, other reasons included financial difficulties of the employer, or a liquidation of the company they worked for, contracts coming to an end, or other personal issues, not related to their condition.

In general, it appears that experts we interviewed support the view that people diagnosed with schizophrenia, as a group, should not be overlooked for a role because of their condition. Emphasis must be placed on assessing the abilities and skills of each individual.

I really think it's about helping to fit the right job to the person rather than the other way around. Nurse consultant

I'd have to look at it individually... I would expect them [the manager] to seek advice and then we would look at the individual and the job and then take it from there. Employer

Similarly, jobs often seen as unsuitable were those involving decision-making or high levels of interaction with customers (Scheid, 2005). Our evidence showed that for some individual's these were the roles that had the most importance.

They didn't think I was suited to be in customer service, they thought I should work in the kitchen and do the tables, rather than do the customer service. That was reasonable, I didn't explain to them that I was on medication... I think they just knew, I don't know why, I don't know how they knew that I was better off cleaning tables and working in the kitchen, although they did tell me I could work. So it was they gradually came round to the point I could work on the service counter giving people their shoes. Lived experience

Customer interaction was seen as valuable, with talking to customers perceived to be a useful distraction. This is despite evidence that people with schizophrenia are often viewed as unsuitable for roles that involve high levels of customer interaction.

I'd quite like to be a teaching assistant. Or I applied for a marketing assistant. The teaching assistant you always get to talk to people. The marketing assistant I think it would involve a lot of people. I'm not like a people person, it's just another way of distracting me, by being involved. I do like talking to people quite a lot because it's not like I'm out there or anything, I just like talking to people. Lived experience

Talking to them, the customer, telling them why their passports weren't available, and when they would become available, and what the problems were. I enjoyed explaining that to the customer. Lived experience

What type of job is appropriate for an individual with schizophrenia can be seen as reflecting them as individuals. It was highlighted that different people have different skills, interests and qualifications as with the broader population. The diverse

combinations and persistence of symptoms for those diagnosed with schizophrenia contribute to different patterns of recovery, meaning abilities to perform job-related tasks will vary with each individual case (Marwaha et al., 2007).

I would not say there was one particular type of work for people with schizophrenia. You've got to take into account their capacity, their motivation and intelligence – it varies. There is not one job that you could say people with schizophrenia are better at. Expert with Lived experience

Everyone is different. I've got a case load currently and I've got maybe seven people with schizophrenia and they're all different. Employment worker

He's very personable. He's very capable of actually understanding processes...., he can understand a series of tasks and doing that, that's not an issue for him. Employment worker

Experts interviewed highlighted that the current situation of low employment opportunities and increased competition for positions would likely make things more difficult for those with the additional hindrance of poor work history, an issue exacerbated in cohorts, such as people with schizophrenia, who may have a distorted work pattern.

We need to go back a bit, see what you can do, what you can't do, have you worked in the past or done voluntary or done work experience? All the answers were no so I had to start at the very beginning with that particular individual. Employment worker

Family members and carers we interviewed were more likely to have a prescriptive view of what types of work people with schizophrenia would be capable of. The perception of what types of job were seen as suitable for the person they knew, varied between family members/carers, indicating that views on this are based on their personal experience of the individual they know.

Something that she likes, looking after children. I said as long as it's something that's not too much information for you. Like practical stuff. Carer/Family member

I know that he'll find something better. I know that he'll find something better, something that will suit him more. He's so intelligent....I am sure he could do anything he put his mind to it really. He could do anything. Just maybe like a job that's going to pay well, because he's got as I say a degree, and I am sure. Family member

3.4. Societal barriers to employment: Welfare Benefits and the Healthcare system

Whilst the benefit and welfare system is a vital intervention in supporting many people with schizophrenia, for some it is seen as a barrier to employment. It has been argued that many people who potentially could work may not attempt to do so for fear of losing their benefits and not having sufficient income. This is known as the benefits (or welfare) trap, wherein taking a low-paid employed role may seem like too great a financial risk given the consequent loss of means tested benefits, particularly for those with dependent children or partners. There is evidence that under previous welfare systems it has been more difficult to exit for people with severe mental illness than the general population because of additional disability payments (Marwaha & Johnson, 2005; Turton, 2001).

If he can't get any more help he is losing out, I don't know if he's getting any more help from the housing benefit or tax credits. But if he's not getting those things then he's worse off. If he's not working then he'll get housing benefit paid and more and more housing benefit paid, so that's what would, that's a disadvantage. Family member

Successive governments have sought to address this potential barrier. The Welfare Reform Act (2007) was intended to reduce this effect, by replacing Incapacity Benefit, Severe Disablement Allowance and Income Support with a single Employment Support Allowance (ESA). This focus on encouraging those with a long term health conditions to return to or commence employment has been continued, and even arguably increased, under the current Coalition government. Unfortunately due to recent nature of these changes in the welfare system there is little research thus far into whether the introduction of ESA has lessened the impact of the benefit trap.

A recent attempt by the current Coalition government to address the benefit trap was the decision to place a 12 month time-limit on the contribution-based ESA Work Related Activity Group (WRAG). The WRAG group is for claimants who the Department for Work and Pensions (DWP) consider will be capable of work at some time in the future and who are capable of taking steps towards moving into work (work-related activities), as opposed to the support group who are those assessed as having such severe health problems that there is no current prospect of their being able to undertake work or work-related activities.⁶ After 12 months in the contribution-based ESA WRAG group the

⁶ <http://www.benefitsandwork.co.uk/employment-and-support-allowance/esa-glossary/1345-work-related-activity-group>

claimant will be moved to either income-based ESA WRAG (a means tested benefit) if they are eligible, or to Jobseeker's Allowance (JSA), where they will receive less benefit and will face greater requirements and stronger potential sanctions.

It is unclear whether placing this time limit on contributions-based ESA WRAG will be effective, as research indicates that this is not a sufficient period of time for many people with mental health conditions to find sustainable employment. Research commissioned by the DWP found that of all of those placed in the ESA WRAG group, only 26 per cent who had been in employment prior to claiming ESA had made it back into employment 18 months after first being contacted by the research team. Of those who had not been in employment prior to claiming ESA, this figured dropped to only 9 per cent (Sissons, Barnes, & Stevens, 2011).

At the time of writing (January 2013) the benefit systems is once again about to undergo a period of immense change. The introduction of Universal Credit (UC) from October 2013 is intending to do even more to prevent people from falling into the benefits trap. Rolling together the majority of means-tested benefits, (including Working Tax Credit, Child Tax Credit, Housing Benefit, Income Support, income-based Jobseeker's Allowance and income-related Employment and Support Allowance), UC introduces a constant 65 per cent withdrawal rate (Department for Work and Pensions, 2010). This reform aims to remove barriers to people undertaking part-time work, as well as removing the 'cliff edge' that many encounter if they want to work over 16 hours a week, beyond which an individual is at risk of losing a significant proportion of their benefit under the current system (Department for Work and Pensions, 2010). Universal Credit will be administered primarily online, with changes in the amount an individual earns (if they are on Pay as You Earn or PAYE) being taken into account automatically. These changes will have an important impact on the way in which people with severe mental health conditions interact with the benefit system, and will effect the barriers that are described in this section.

One example of the potential impact of UC on barriers within the benefit system is its potential for flexibility. Interviews with experts highlighted that the rigidity of the current benefits system was a cause for concern for people with schizophrenia, given the variation in symptoms and possibility of relapse which may cause them to lose or leave jobs. The latter was a particular concern, as someone may feel they have to leave a job due to a work situation, leaving them without benefits as this would be a voluntary resignation.

It was identified that if it was possible to facilitate easier transitions in and out of the benefits system, this might assist the dilemma. In theory UC may help this, as it is designed to be more responsive to changes in individual circumstances (Department for Work and Pensions, 2010).

It was frequently mentioned by our interviewees the impact the benefits system had on people they knew – with several giving examples of undertaking appeals in relation to loss of benefits, and employers and health workers having to get involved to assist with this.

If she is on benefits, maybe the lowest lowest lowest, because she was telling me, "Mum, I have to go to court because I have to fight them taking my benefits". Family member

I then spent a bit more time talking to her about it and actually helped her. I said, "would it help if I wrote a letter to them explaining the time that you worked with us so far, and the fact that from our employment experience with you, you couldn't actually do any more work than two or three days a week?" Employer

The conditionality of disability related out-of-work benefits such as ESA have been made tighter, with the introduction of the Work Capability Assessment (designed to assess whether a person should be placed in the Support or WRAG group, or whether they are 'fit for work') and an increase in the level of sanctions for those claiming ESA WRAG if they do not attend the work focused interviews or the work related activity that they are expected to attend. It should however be noted that there is mixed evidence regarding the effectiveness of sanctions in encouraging people back into the labour market. Whilst it might encourage people to exit the benefit system, and also lead to a short term rise in employment, a literature review undertaken by the Joseph Rowntree Foundation found that in the studies there was little consistent evidence to suggest a long term positive effect. The report also suggests that sanctions generally lead to unfavourable effects on longer term outcomes such as earnings over time, child welfare and job quality. This would suggest that although the threat of sanctions might lead to a short term reduction in the number of people claiming ESA, in the long term it might not be an effective policy (Griggs & Evans, 2010).

The stress of worrying about benefits was also seen as having an impact on their ability to work.

She, I think with the changes in working, I am not quite clear, it's all about the benefits. Because she was only working part time, I think the Benefits Agency was

trying to say that she should be fit enough to work full time, and therefore she would be penalised in her benefits. She was trying to do everything herself, the appeal and going to the actual appeal hearing. It was only by accident when I was having a conversation with her, she said to me I am in a bit of a tizz because I can't really focus on my work at work. Employer

This is particularly the case where someone with schizophrenia may not be able to appropriately convey the extent of their condition. Studies have found that in some cases people with mental health conditions may underreport their symptoms for a variety of reasons (Slade, Phelan, Thornicroft, & Parkman, 1996).

Because people like my son are going to be hugely disadvantaged by these tests. Because he hasn't got a voice, like many, he has not got a voice to deal with people like that. That interview him, "what can you do, how does your illness affect you?" He's not able to explain and he doesn't think he is ill, so he would say to them "I'm not ill, I'm alright". Carer

I'll give an example of another person ... he's got schizophrenia, he's not been at work for 20 years, so he's actually not working, and they were trying to get him back into work, because he failed the test. We had to help him do the appeal as well, with another organisation. He won the appeal but he only missed by two points in the medical assessment. It's really stupid. Because he actually wrote on the form himself, and said that he could work. Subsequently, I think there is a pressure when you fill in a form, and if you don't have any guidance you just think I don't want to tell people I can't work and I'm useless. Because it impacts on your self-esteem, all that kind of stuff. Employer

It also appears that there have been problems with applications being dismissed as being 'fit to work' when this is not appropriate. Though there is widespread support for the stated aims of the Employment Support Allowance (ESA), criticism from a variety of quarters, including the third sector, has been levied at the process by which eligibility for the support is assessed, the Work Capability Assessment (WCA). There has been a high rate of appeal, with 39 per cent of all Fit for Work decisions for new claimants appealed against (this group does not include people who are being transferred from Incapacity Benefit to ESA). If a person is declared Fit for Work they are not eligible for ESA and must claim Jobseekers Allowance (JSA), a smaller benefit which requires the claimant to seek employment (Department for Work and Pensions, 2013). Worryingly, 60 per cent

of people who had their decision overturned between October 2008 and February 2010 had scored zero points in their initial Work Capability Assessment – in other words their assessment had found that they had no factors limiting their ability to work.⁷

I remember once he applied for disability benefit, he applied for that and he didn't get it, so that was another setback. He applied for it because we could see that he couldn't be working because he had mental health but he didn't get it. So he just carried on not having much money, I wasn't even sure if he was signing on, he must have been. Yes. He didn't have much money so hasn't got, he had no help. Family member

The WCA is seen by some as particularly problematic for those with mental health conditions, and argue that the assessment does not take into account the fluctuating nature of mental illness when approximately 53 per cent of those claiming ESA have a 'fluctuating condition' (Sissons et al., 2011).

There is also evidence to suggest that whilst the majority of people who dropped their ESA claim during the application process did so because they were not eligible for the benefit, there was a minority of vulnerable people who were unable to apply because they could not manage the claim process. This group, which often includes those with a mental illness, found the claim process overwhelming and no assistance was available for applicants in completing the application (Barnes, Oakley, Stevens, & Sissons, 2011).

There are also issues surrounding cases in which people with primarily mental health conditions, are being assessed on their physical abilities (Barnes et al., 2011).

Someone assessing you for 20 minutes, questions to do with physical ability – that really annoys me. They were asking me more whether I could move a limb rather than asking anything about my mental health. Lived experience

New legislation regarding the Work Capability Assessment will be introduced at the end of January 2013 which will prevent this from occurring. This legislation will mean that physical inability must be linked to a specific physical illness or disease, and that a mental inability must be linked to a specific mental health condition.⁸ Whilst this might lead to a greater focus on the mental health needs of the individual, there are concerns that this may ignore the impact that mental health conditions can have on a person's physical abilities.

7 <http://www.theyworkforyou.com/wrans/?id=2011-06-28b.61405.h&s=Work+Capability+Assessment+2011-06-28..2011-06-28>

8 Social Security - The Employment and Support Allowance (Amendment) Regulations 2012 http://www.legislation.gov.uk/uksi/2012/3096/pdfs/uksi_20123096_en.pdf

The assessment process and the process of applying for jobs were spoken about negatively by all those who raised it in our interviews. The negative impacts on individuals with schizophrenia going through the assessment process was a clear concern, and for some the requirements are seen as unrealistic and putting people under unnecessary stress.

The requirement was that if you go to Job Centre Plus you have to apply for so many jobs a week, and you have to fill in this form and you have to do quite a lot of – it's actually quite horrible what you have to do. Imagine if you have any kind of mental health illness, particular schizophrenia how that impacts on you. He was getting really confused. Employer

The Work Capability Assessment has come under heavy criticism from a number of quarters, with numerous disability rights activists and mental health charities expressing their fear that the process is harmful. Campaign groups have called for the assessment to be overhauled.⁹ There is some evidence to back up these fears, with a survey, commissioned by the mental health charity Rethink Mental Illness, of GPs with patients with mental health conditions who were going through the WCA finding that one in five have patients who have had suicidal thoughts as a result of undergoing, or fear of undergoing the WCA. 75 per cent said that their patients had been negatively affected by undergoing, or fear of undergoing the WCA, and needed extra support from their GP as a result (Centre for Mental Health et al., 2012).

Back to work support

The government's flagship employment scheme, the Work Programme, has faced criticism regarding its efficacy in helping people with mental health conditions return to work. The Work Programme is based on a payment by results approach in which back to work support is entirely contracted out to 18 organisations, 14 private and 4 not-for-profit. These organisations then subcontract to a mixture of private and voluntary sector organisations to help provide employment services. These service providers will not receive the majority of their funding until the participant has been in employment for either 3 or 6 months, depending on the claimant. The Work Programme model is based on a 'black box' approach, where there are few guidelines dictating what services contractors must provide, with, in theory, each provider offering a tailored

⁹ 'New GP survey shows Government welfare test is pushing vulnerable people to the brink' (Rethink Mental Illness, 4th September 2013, http://www.rethink.org/how_we_can_help/news_and_media/national_press_releases/new_gp_survey_shows.html) & 'Why the WCA isn't working' (Mind, 2nd April 2012, http://www.mind.org.uk/blog/6632_why_the_wca_isnt_working)

programme of support individual to each participant's needs. The inclusion of specialist organisations and charities is intended to provide tailored support that otherwise may not have been available through general government programmes.

When and if an individual is referred to the Work Programme depends on the benefit type that they are on. If they have a diagnosed severe mental health condition, such as schizophrenia, it is likely that they are claiming ESA, and are in either the Work Related Activity Group or the Support Group. Placement in the Work Programme can be either voluntary or mandatory depending on which group they have been placed in, their own wishes, and whether they have been deemed ready to work.¹⁰

People who have a mental health condition or learning or behavioural disorder as their main disabling condition are the largest group of people claiming a disability-related benefit on the Work Programme. Despite this their success rate is thus far low, with only 1.1 per cent of people in this group successfully reaching their expected job outcome length (either 3 or 6 months). However, job outcome rates have been low for all groups – 1.6 per cent for other primary health condition categories claiming a disability related benefit and 3.8 per cent for those claiming JSA.¹¹ As the Work Programme has only been in existence for just over a year at the time of writing and participants are referred to the Work Programme for two years, it is possible that these figures may improve.

The payment-by-results model on which the Work Programme is based may also negatively impact on the scheme when it comes to harder to help job seekers such as those with severe mental health conditions. There is already evidence that charity sub-contractors in the Work Programme, who are more likely to work with those with mental health conditions due to their specialised nature, are suffering. In an NCVO survey of its members who are sub-contractors in the Work Programme a third said that they had yet to receive any referrals and about half said that referrals were significantly less than expected. This is a problem, and one that has already led high-profile charities such as St. Mungo's to leave the programme. It looks as if other charities are also worried that they may be forced to leave as well, with 71 per cent saying that they believe their contracts are at risk of failure in the next six months (Winyard, 2012).

The financial burden of setting up support infrastructure before receiving payment is exacerbated by the fact that ESA claimants, who come with a much higher payment for success than Jobseeker's Allowance claimants, have not been referred to the Work Programme in the quantities forecast in the Invitation to Tender. Only 34 per

10 'ERSA policy briefing: The Work Programme' (The Employment Related Services Website, May 2012 <http://ersa.org.uk/documents/ersa-policy-briefing-work-programme>)

11 Department of Work and Pensions tabulation tool (<http://83.244.183.180/WorkProg/tabtool.html>)

cent of the predicted ESA and Incapacity Benefit (IB) claimant volume have actually come through, partially a result of slower than expected implementation of the Work Capability Assessment and the high number of appeals.¹² This hits sub-contractors in the charity sector disproportionately hard, as they are more likely to be dealing with these claimants.

If charity sub-contractors who specialise in mental health and schizophrenia are not getting the referrals they need and are forced to leave the Work Programme this will have two important impacts on those with schizophrenia. Firstly, the specialized support people with schizophrenia need to enter employment will no longer exist within the Work Programme, or at least not at its current level. Secondly, contract failure may have important financial implications for the charity. This has the potential to either reduce the services that the charity provides, or even cause the charity to close. This would reduce overall services for those with schizophrenia at a national level. Reduced support for people with schizophrenia, both in the context of the Work Programme and outside it, would present an important barrier for people returning or entering the work place.

There are also issues and concerns surrounding other employment programmes which may impact on those with schizophrenia and other mental health issues, and represent a barrier to this group returning to work. The Work Choice programme, which replaced WORKSTEP and Work Preparation, is a specialist employment programmes for those who are disabled as defined by the Equalities Act 2010, and are claiming ESA or JSA (but were claiming IB before claiming JSA).

The first module lasts up to six months, and is focussed on helping the participant find employment, while modules two and three focus on supporting the individual in this role once they are employed. However, despite the programme's focus, only 250 people with a severe mental health condition have been referred to the scheme since 2010. It is also concerning surprising that Prime Contractors only have six months to place a participant in a sustainable job, compared to the two years that Work Programme providers have to work with people¹³. Whilst the programme does provide support once the participant is in employment, the relatively short window of opportunity in which they have this intensive job search help may mean that the programme is not effective for those hardest to help – a category which may include those with schizophrenia.

12 'Work Programme referrals and attachments: Inclusion analysis' (Centre for Economic and Social Inclusion, 7th November 2012, <http://www.cesi.org.uk/keypolicy/work-programme-referrals-and-attachments-inclusion-analysis>)

13 http://base-uk.org/sites/base-uk.org/files/news/12-01/base-ersa_letter.pdf

Healthcare services – Physical and Vocational Outcomes

I think just a quick observation, I think that's indicative of the place of work still within many mental health services, from my perspective we know 80 per cent of the mental health has been going on about this for years, but we know that 85 per cent of service users with severe mental health needs would like to work. That suggests to me that really it should be if not the top outcome, then certainly one of the top three outcomes. Other ones being accommodation and so on. I think functional outcomes are very, very important, it's difficult to get them to the top of the agenda. Again it's my answer would be the top answer. Vocational Manager

The 2012 Audit on Schizophrenia (Royal College of Psychiatrists, 2012) found higher risks for physical health problems and worse physical health outcomes for people with schizophrenia against the general population (see section 3.1). The Audit identified that only 29 per cent of people with schizophrenia in the health system received a comprehensive assessment of important cardiometabolic risk factors (such as BMI, smoking status, family history and hypertension). The Audit highlighted that this was true of very simple screening measures – only 56 per cent of service users were reported to have been weighed during the previous 12 months, and basic information about diet and exercise for those with a high BMI was not seen in a quarter of cases. Treatment or further investigation of health problems and areas which should warrant concern such as high blood pressure or cholesterol levels, also rarely occurred.

Within the interviews, a further concern about the healthcare system itself was that mental health services were not well-coordinated or 'joined up' with one another and the broader health and social system. Factors interplaying with this included the impact of changes within health service structures and teams, and a feeling that no one was in charge of the care team.

Professionals are so un-joined up and fragmented, that there is nobody really in charge of my daughter. She's had seven psychiatrists in several years. There's a social worker in the background but she's very passive. Carer

Despite it's inclusion in the Commissioning Board Mandate, and both the Mental Health and Physical Health Outcome Frameworks there was a suggestion that the role of employment is not prioritised as an outcome of health and social care services, or even considered to be an outcome by the healthcare team. This was understood as being due to healthcare providers not having sufficient time during health appointments to deal with such a wide range of issues. It was suggested that referral structure should not only include psychologists, but also befrienders and peer support workers, which might

alleviate the pressure on healthcare providers while still provide services and support to patients. The impact of funding cuts to certain health and social care provisions is also identified as having an impact, particularly by those experts working on healthcare provisions.

It's certainly something that I think mental health professionals at least now know that they should be asking clients about. I don't think it happens as often as it should. I don't think people are asked often enough. I think the expectations for people to get them back into paid employment and education are still too low. Nurse consultant

It was argued by some experts, that work should not be seen as a priority for people with schizophrenia because primary outcome should be *to remove the distress of that illness and help their symptoms get better*. It was emphasized that other outcomes, such as work, should not be ignored, but actual support for them may fall outside the realm of the health service.

What health professionals need to do is try to improve the patients physical health as much as they can, or mental health, and then have an open mind to try letting them go and try to work if they want to. Not to stand in the way. Academic psychiatrist

It cannot be assumed that everyone with a diagnosis will have the same ability to work, and care needs to be taken to consider the needs of individual people, and how employment affects each individual. Among carers and family members we spoke to, views were very different, depending on the individual. Throughout our interviews with experts there was, however, broad support for the concept of work being a realistic outcome for many people with schizophrenia. This support was to varying degrees, which might be seen to reflect the relative closeness of the role to the vocational rehabilitation function. Perhaps unsurprisingly, positive views were strongest among those with a larger role in this area. As illustrated below, the occupational therapists, vocational workers and psychologists were very positive about the role of employment in recovery, while at the other end of the spectrum, one psychiatrist we interviewed, emphasized that it was less of a clinical outcome, more of a social outcome for a minority of people with schizophrenia:

Healthcare workers see employment as a small priority. Social outcomes are never primary and there is no reason why they should be. Academic psychiatrist

The belief of our profession is that work is a good thing, it is part of treatment and we are more positive when it comes to what people are able to do. We consider that having

an occupational life, having routine in your life can aid recovery. Work can help people getting better. Occupational therapist

I think that work is hugely stabilising for people and really can only benefit the individual and the people in their environment and their social circle. Psychologist

Overall, for those with schizophrenia, the role of non-clinical outcomes was seen as far more important.

I think healthcare professionals are far too weighted on the clinical side of things – people can have control and can go back into the world Lived experience

3.5 Barriers to employment: Employers experiences of people with schizophrenia

Employers and organisations play two major roles as regards the employment of people with schizophrenia. They will decide whether to employ a person with a disclosed diagnosis of schizophrenia – considering this factor alongside the usual factors of skills and experience. They will also be responsible for the work environment and providing support.

Much of the discourse regarding the employment of people with schizophrenia is rightly from the perspective of the needs of individuals with schizophrenia. It is also important to consider the perspective of the employers, and the perceived and actual barriers which may be preventing them from employing people with schizophrenia.

In this section we consider some of the barriers from the employer perspective, and consider ways in which they have been and might be addressed.

Stigma and Awareness

Discrimination from employers and co-workers, has been identified as a major barrier for individuals with schizophrenia in gaining and maintaining employment (Mental Illness Fellowship of Australia Inc, 2007). It has been indicated that employers' negative attitudes have led to reluctance to employ people with mental health conditions, and particularly those with a severe condition such as schizophrenia (Manning & White, 1995).

It's an on-going battle really... a lot of it is to do with raising awareness for the managers so that they don't sort of look at a disability of any sort and write somebody off. Employer

Employers indeed hold strong beliefs about the impact of severe mental illnesses on an individual's ability to work. In a survey of employers, 67 per cent reported they were uncomfortable employing a person taking antipsychotic medicine, while half (53 per cent) reported being uncomfortable taking on people with a previous mental health related hospitalisation, and 43 per cent uncomfortable employing a person being treated for depression (Scheid, 2005).

Poor treatment by or a lack of support from colleagues have been highlighted as presenting a barrier, particularly in terms of job retention (Nithsdale et al., 2008). This is seen as reflective of colleagues' negative attitudes as well as their own anticipation of discrimination. Though not a recent example, our interviews did highlight the impact of negativity from colleagues on someone with schizophrenia's efforts to work.

He wants a better life, he doesn't like his life the way it is. But realistically he knows he couldn't hold a job down. He did like a work experience, it was YTS¹⁴ back in his day when he left school on the building, he really wanted to do that, he really wanted to do it. But of course he gradually slid downhill and he was being bullied and picked on and the YTS people pulled him out. He was saying no - he persevered with it, he said no, leave me here, I want to do this, they'll get fed up of taking the P basically but they didn't and it got worse and worse and worse. And for all he mouthed and aggression, he's actually like a little frightened rabbit when it comes to it. Carer

Recent years, however, there has been an encouraging increase in awareness among employers in the UK of how common mental health conditions actually are. Surveys of employers in 2006 (Shaw Trust & Future Foundation, 2006) and 2009 (Brohan, Henderson, Little, & Thornicroft, 2010) showed the proportion of employers who believed none of their employees would develop a mental health problem during their working lifetime dropped from 33 per cent to 7 per cent (Little, Henderson, Brohan, & Thornicroft, 2011). It was indicated however that employers' perceived awareness of mental health conditions may not stretch to severe and enduring conditions, such as schizophrenia. When employers were asked which disorders they associated with mental ill-health in the workplace, only 3 per cent in 2006, rising to 12 per cent in 2009, identified schizophrenia. Depression and stress were the most commonly identified (Little et al., 2011). This implies that, when employers are talking about mental health in the workplace and ways in which they can support people, they may not be seeing this in the context of more severe conditions.

14 Youth Training Scheme

I'm not really sure to be honest if my perception has changed, I don't think I really had one before. Employer

In our interviews, employers were asked specifically about schizophrenia. Their responses showed awareness that schizophrenia and other mental health conditions could be more common in their organisation than they were aware of:

I've only come across one individual that I am aware of with schizophrenia. There are likely to be more employees considering the number of employees that we've got. Employer

We're conscious that there are probably a number of people that have suffered it [mental health problems] or do suffer it currently that haven't been so open. Employer

It is apparent from the research evidence that employers do not have enough information on mental health, how to support people with mental health conditions, and the impact of this on work (Little et al., 2011; Manning & White, 1995). Given the paucity of information, it may not be surprising that employers who have not had direct experience employing someone with a mental illness, may not understand what the implications are of particular mental illnesses for them and for their employees.

According to the Employer Surveys (2006 & 2009) a large proportion of employers, increasing from 67 per cent in 2006 to 81 per cent three years later, believe that a low awareness of how to help support people with mental health issues in the workplace has led to a loss of talent.

Education and training to improve mental health literacy in this area may help to improve employers understanding of mental health, and how people can be supported. Little (2011) concluded that practical training and guidelines for managers would be well received by employers. Breaking down the negative assumptions which feed the stigma about people with schizophrenia and severe mental health conditions, is a fundamental factor. Educational programmes have been highlighted as being effective in improving attitudes about people with mental health problems, and lessening negative stereotypes across a variety of groups (Corrigan & Watson, 2002). The education approach is not always successful, with some evidence indicating that education and increased mental health literacy may not negate the emotional response, including a belief that people with mental health conditions are dangerous (Angermeyer, Holzinger, & Matschinger, 2010; Hand & Tryssenaar, 2006). Tackling emotional responses and highlighting employer subconscious bias might be avenues for investigation (Angermeyer et al., 2010; Tal, Moran, Rooth, & Bendick Jr, 2009).

Another way of addressing stigma and negative stereotypes, is by actually meeting an individual. Evidence suggests that stigmatizing views about people with mental health conditions can be addressed simply through contact (Angermeyer et al., 2010; Brohan, Henderson, et al., 2010; Couture & Penn, 2003).

The strongest attitudinal opposition is when you haven't actually met the person. I think once you get to know the individual with their disabilities and quirks, then on the whole the stigma tends to evaporate a bit. Academic psychiatrist

Personal and social contact is seen as more important than work-based contact. Brohan, Henderson, et al. (2010) identified that stigma was further reduced when contact was social and not work related. The importance of the personal relationship was to some extent reflected in interviews, where one employer who had personal but not professional experience of someone with schizophrenia placed considerable emphasis on the importance of looking at the whole person, not just the diagnosis.

It would depend on what the individual's skills [are]. We wouldn't just need to look at schizophrenia, we'd need to look at what skills and attributes and experience they've got. Employer

For an individual with schizophrenia, getting to know colleagues better might be seen as a way of developing better working relationships, and consequently increasing their own confidence.

I think if you're working as a team at work, it's really good to go for like – I'm sure they do this already, like team activities. To really find out about one another in a personal level as well so that you can work well together. Lived experience

Better relationships also lead to greater understanding, and acceptance of the reasons for unpredictable behaviour which is sometimes seen in people with schizophrenia whose symptoms are not being appropriately managed. In one example we were given, it was explained how after an incident had occurred with the employee with schizophrenia, impacts were minimized by the understanding shown by colleagues, based on the previously built relationships. Even in such an extreme case as this, disclosure of the condition (on a need to know basis) joined with prior knowledge of the individual, was seen to have a protective effect, and colleagues showed understanding.

It took a lot of negotiation to be able to resolve it but we got there in the end, because she had actually said that prior to that incident, she found him to be an extremely nice guy who'd always say good morning. He always came down in the mornings to get the

post or whatever and he'd always have a chat with them and a laugh. And they could see that it was completely out of character for him to behave the way that he did. Employer

The impact of previous employment experience on future employment was less clear. Hand & Tryssenaar (2006) identified a significant association between non-work contact with people with mental illness and an employer's willingness to hire. This association, though present, was not significant when looking at work contact. There is some evidence that previous employment experience may not be linked to future likelihood to hire. Brohan et al. (2010) found a positive relationship between experience of hiring someone with mental health problems and concern about the impact of symptoms. This suggests that increasing employment experience may not help employers to feel more confident in managing individual cases with severe mental health conditions.

Overall, the employers we interviewed were generally positive about the idea of employing someone with schizophrenia in the future, based on what they had learnt through their experience to date. It was anticipated that making the adjustments and supporting them would be a less time-consuming given what they now knew. Though it was still made clear that individuals will have different needs and their needs would have to be assessed individually, and that this would be a consideration in future employment decisions.

Legislation and Company policy

Legislation has been put in place in the UK aiming to reduce discrimination within the workplace (the Equality Act 2010, following the Disability Discrimination Act). In response to this we have seen the inclusion of mental health in the general disability policies of many organisations (Brohan, Henderson, et al., 2010), and even a specific mental health policy in some. In 2009 two thirds of UK employers reported knowing enough about the law regarding mental health in the workplace, and agreed that managers in their organisation had a good understanding of mental health issues (Brohan, Henderson, et al., 2010). It is interesting to note that employers with previous experience of employing someone with a mental health condition were more likely to identify that they did *not* know enough about the law regarding mental health in the workplace (Brohan, Henderson, et al., 2010). This might imply that getting things right in terms of policy relating to legislation may be more difficult than many employers believe.

Little et al. (2011) highlighted that less than a third of the companies responding to an employer study (Brohan, Henderson, et al., 2010) had a formal policy on stress and mental health, showing little change from the situation three years previously (Shaw Trust & Future Foundation, 2006). It was suggested that this signifies poor impact of the concerted efforts to undertaken to improve employer's legal knowledge in this area.¹⁵

There are some concerns that even those who have developed policies addressing mental health may have done so for the protection of the organisation, rather than actively trying to reduce discrimination against people with mental health condition. For example, in the employers surveys, 51 per cent (in 2006) and 34 per cent (in 2009) of employers reported that they had a specific policy for mental health and stress and that the policy was primarily designed to help their organisation avoid litigation (Little et al., 2011).

The employers we interviewed did not have specific mental health policies. For some it is seen as no different from any other condition, all of which they would seek to provide support for.

There is nothing specific to say if you have mental health we will treat you in a different way. But obviously if you have a particular need arising from any illnesses including mental health, we will work with you to address those needs. Employer

Lack of a specific policy should not be seen as an indicator that employers are not taking an active approach to addressing mental health in the workplace, with one interview highlighting that this can come in different forms.

We put together a group of people from around the organisation that were kind of focusing on mental ill health and stress awareness and so on. So we had a couple of open days and programmes, posters and emails and communications to try and encourage people to be open about it. Employer

In terms of other policy avenues for support, it was identified that 75 per cent of employers had internal human resources, 30 per cent had an outsourced occupational health service, and 18 per cent had an outsourced employee assistance programme. Over 80 per cent of employers surveyed stated that they had a designated route for managing people with mental health problems (Little et al., 2011) – demonstrating the

15 SHiFT Line Manager Resource: Updated Edition (<http://www.docstoc.com/docs/12705341/Shift-Line-Managers-Resource-Updated-Edition>)

increased awareness of mental health as a common issue among employers. What these pathways entail and whether they are seen as helpful for people with mental health problems cannot be assessed from this.

Smaller organisations with fewer employees will be less likely to have had experience of employing someone with mental health problems and therefore are likely to have less knowledge about the laws regarding mental health and employment, and less likely to have a disability policy (Brohan, Henderson, et al., 2010). Smaller organisations are also less likely to have a Human Resources department and may have limited access to occupational health services – both considered to provide valuable services and support for employees with severe mental health conditions. While larger organisations are more likely to refer employees with a mental health condition to occupational health, employers at smaller organisations are more likely to broach issues themselves (Fenton, O’Hanlon, & Allen, 2003).

Poor understanding of the policy and legislation around disclosure was also apparent from employer surveys. The Equality Act 2010 banned the use of pre-employment questionnaires. Prior to this, as evidenced by the Shaw Trust (2006) and Brohan, Henderson, et al. (2010) surveys, more than 75 per cent of employers reported that they would ask prospective employees to disclose mental health problems prior to employment – be that at the application stage, prior to interview, during the interview, at an occupational health assessment or at the job offer stage (Little et al., 2011). Given the timing of the studies, it is unclear whether the changes to the Act have impacted on employers expectations, though Little emphasises the importance of raising employers awareness of the amendment and to provide legal assistance to those who may have a possible case of discrimination.

Employers interviewed stated a preference for disclosure of condition prior to taking on a role, but respected why this often did not occur.

I think it’s a shame that a lot of people who have suffered mental ill health problems won’t declare it on their job application anywhere. Quite understandably, because a lot of employers will see that and turn them down. Employer

Work Environment, disclosure and support

Employers will not be able to provide the right support for an employee with schizophrenia if they are not informed about the condition. It is therefore in the interests of employers to facilitate an environment in which an employee might feel more comfortable disclosing their condition. Other benefits of disclosure may include raising

awareness of the condition, and through disclosure more people will likely become conscious of having had contact with someone with schizophrenia which might help address stigma. In terms of less severe mental illness, one employer we interviewed talked about the measures undertaken in their workplace to raise awareness of mental illness, and the increased disclosure which has occurred as a result of this.

We're encouraging people to come out and be honest with it because by declaring it then we know that we can address it and manage it properly. Employer

The current extent of disclosure among employed people with schizophrenia is not known, and even varied in our interviews. One employer interview spoke of disclosure only occurring after an incident resulting in disciplinary proceeding had occurred, while another was aware of their employee's condition beforehand as they were recruited through a Supported Employment (SE) agency.

Facilitating disclosure of a highly stigmatized condition however may require a change to the working environment. Employees may need to be assured that it is safe for them to disclose, as they may be fearful of the response. Employees will also be less likely to disclose and seek help if there is not a clearly defined, easily accessed route for doing so. It may help if they are aware of what the process will entail, including the reassurance that they will be able to maintain control or have substantial input into what happens next. Employees might be encouraged by being made aware of the types of supports that could be available to them if they did choose to disclose.

Disclosure, however, must be the decision of the individual – it is a choice. When an employee has chosen to disclose to a manager or employer, then further disclosure might be considered by both the employer and the individual. This might depend on the situation. For example, an employer we interviewed from a larger company felt it was only appropriate to disclose to a few people who were directly involved with supporting the staff member. While an employer from a very small organisation felt that in this context all staff could be made aware. In both cases the needs of the individual were the primary consideration.

It is only through disclosure that employers have the opportunity to make the adjustments and provide the support that a person with schizophrenia might require in order to work to the best of their ability and maintain their employment. Where disclosure occurs at an early stage, incidents which may have otherwise occurred as a result of the illness may be prevented through adjustments being made straight away.

Though emphasised for facilitating disclosure of a mental health condition by an individual, it is important to note that a supportive work environment is an important factor in job retention for every employee. It was stated in our interviews that much of the workplace support available for someone with schizophrenia, is the same as should be available for all employees. This is something seen in the Responsibility Deal, which highlights the importance of a good working environment for the wellbeing of all and particularly in terms of the recovery of mental health conditions.¹⁶

I guess it would just be the same for anyone, it's not just schizophrenia. It's speak to the individual, find out what causes them difficulties, ask them what could potentially resolve it and if you can, within reason as an employer, practically put them in place.

Employer

These types of support, and supportive environments will also be valuable for someone returning to work after a period of illness.

It's also helping people to recognise that certain things may be difficult but there are ways of overcoming and coping with them. There are difficulties when you get back to work. So it's about supporting, it's not just saying oh well, you're going to be fine, go back. It's also providing support in the workplace and support in getting people back into work. Psychologist

A supportive work environment can enable people to remain in work by making people feel that their needs are accepted and that they can ask for help and support when it is needed. Disclosure is encouraged as a supportive environment means people will feel that they will be supported to do better in their work. The importance of getting information early and providing support early, was emphasized throughout the interviews, even in our example of an employee who presented with extreme symptoms, with the employer feeling that they could have prevented the incident from occurring had they been better informed about the individuals condition and needs.

The reason that we didn't dismiss him was that we felt we just didn't know enough about his condition and therefore probably hadn't put enough support in place for him.

Employer

By ensuring everyday support is in place, then the rate of 'bad days' that people with schizophrenia can have, as can everyone else, will likely be reduced. Just because an individual has schizophrenia, this does not automatically make it the reason for their behaviour.

¹⁶ <http://responsibilitydeal.dh.gov.uk/2012/06/26/new-mental-health-adjustments-pledge/>

I think you have to try and understand which bit is actually related to their illness, and which bit is actually they're having a bad day. And the bad day is nothing to do with their illness, they might just be like maybe having a bad day, like we all do. The same problem, there are days when we probably aren't as productive as we are, and that goes with people with schizophrenia or any other form of mental illness. Employer

By making it easier for employers both to employ people with schizophrenia and to provide them with support they need to stay in work, then employers will be more likely to see the skills and experience of the individual employee, which are often obscured by their diagnosis. Interviews with employers showed that with the right support in place, employees with schizophrenia can be as good an employee as anyone else.

I could see she had potential. I saw that she had all the required criteria; I am on [the] appointment panel, so I knew what she was capable of. Employer

He's extremely able. When he is calm and he's taking all his medication and everything is right for him, he's extremely able. I wouldn't say he's a top performer but he's certainly not an under performer either. Employer

Reasonable adjustments

When disclosure has occurred, then employers will need to look at the best ways to support and accommodate employees. Support may be as simple as providing someone for an employee to talk to when they need too. It may also require other simple changes to work patterns, working time and the nature, sequence and complexity of tasks in their roles.

The Equality Act 2010¹⁷ requires employers make 'reasonable adjustments' for employees in the workplace. These are defined simply as a "change or adjustment unique to a person's needs that will enable them to do their job".¹⁸

Reasonable adjustments might include adjustments to:^{19, 20}

- Working hours or patterns, e.g. flexible hours, leave for health appointments, change to break patterns, reduction in hours;

17 <http://www.legislation.gov.uk/ukpga/2010/15/schedule/8>

18 http://www.nhshealthatwork.co.uk/images/library/files/Government_per_cent20policy/Mental_Health_Adjustments_Guidance_May_2012.pdf

19 Ibid

20 <http://www.equalityhumanrights.com/advice-and-guidance/guidance-for-employers/the-duty-to-make-reasonable-adjustments-for-disabled-people/reasonable-adjustments-in-practice/>

- Physical environment, e.g. minimise noise, move workstation, increase personal space;
- Support with workload, e.g. supervision, job-sharing and task prioritisation;
- Support from others, e.g. job coach, buddy or mentor.

Concerns about what the provision of a supportive environment may mean for employers can be a barrier to employment. There may be views that the requirements and accommodations the employer must make will be onerous, costly and/or time-consuming, or they may be concerned about how the situation might impact on other employees.

Prior to the implementation of the Equality Act, there was already an increase in the proportion of organisations who believed they would offer adjustments to someone with a mental health condition (from 68 per cent in 2006 to 87 per cent in 2009). In practice, the extent of adjustments offered may be more limited. The 2009 employment survey showed only 28 per cent of employers had reduced the workload or working hours of an employee with a mental health condition, only 22.5 per cent were given access to counselling, and only 14 per cent the option to work from home (Little et al., 2011).

Advice for employers on workplace adjustments for employees with mental and physical health conditions has been developed by the UK Department of Health,²¹ though it is unclear whether this information is reaching employers, or how useful they are finding it. Adjustments are often low cost, easy to provide and temporary. In our interviews, for example, adjustments mentioned included: providing a buddy to talk to; allowing extra breaks when required; rearranging workstations so people do not have to work with their back to others; and allowing headphones to be used while working. Where adjustments have a monetary cost, Access to Work grants may be available to employers and employees.²²

As previously noted, the ability of an employer to make the most appropriate adjustments will depend on the extent of disclosure, and the amount of information they can access on a given individual's condition and needs. In one employer's interview, they spoke of being lucky in their experience as their employee was very open about their schizophrenia, and they were able to seek advice on adjustments from their mental healthcare team.

21 http://www.nhshealthatwork.co.uk/images/library/files/Government_per_cent20policy/Mental_Health_Adjustments_Guidance_May_2012.pdf

22 'Employers Guide to Access to Work' <http://www.dwp.gov.uk/docs/employer-guide-atw.pdf>

We don't really have any specialists that can help us with giving us more informed information. So for the individual that I mentioned, he did have a specific consultant who was a specialist in that area and so he did give us an extremely detailed report and answered all of our questions, which was extremely useful. Employer

Access to this level of information may not always occur, and employers also identified the lack of information on what to do, and a lack of awareness of where to access support as considerable problems in terms of making reasonable adjustments and providing other support. Sometimes it was unclear what adjustments and levels of support were in fact 'reasonable'. Once employers were more aware of, and had a better understanding of the illness, then they were able to go on to further develop these on an on-going basis with the employee.

They can also come up with reasonable adjustments. And in most cases we can come up with those ourselves, it's a common sense approach, after liaising with the employer and the manager. Employer

It was noted that for many employers, this is new ground and they will be learning as they go. It may take time to find out the best ways to accommodate and support employees with conditions such as schizophrenia – suggesting that more information, guidance and support for employers is needed.

Employers will make mistakes and you've got to learn from them and make sure you don't make them with the next person. But we can't do everything, you have to work within your limits of what's reasonable. Employer

Those with experience of employing someone with schizophrenia suggested that the time taken to provide support is a bigger issue for them than any direct financial costs. In our interviews, it was considered that the experience of employing someone with schizophrenia may put some employers off employing someone in the future, given that it can take some time and effort to manage.

He has taken up an awful lot of management time because he has had a number of episodes that we've had to manage and we've had to put an awful lot of adjustments in place. Employer

The outcome, however, was seen as positive in several interviews, with one stating:

With all those right things in place, it may take some time and some cost but they can still become just as good a worker as anyone else. Employer

The role of the line manager

The importance of having a supportive line manager, or someone in work with whom an employee with a mental health (or other) condition feels that they can talk to, was emphasised as crucial through all the employer interviews. One employer spoke of how having the 'wrong' manager (i.e. someone who did not feel able to provide the required support) can cause an employee with schizophrenia to resign. In fact, having a supportive line manager can be seen as a reasonable adjustment itself.

So there were a number of reasonable adjustments that we put in place, one being making sure that he had the right manager. Employer

The line manager needs to have a good understanding of mental health conditions. The importance of having this source of support came across clearly in the interviews and also how important a supportive line manager can be:

I would say that you need to have the right manager... Having a manager that is open with them and able to meet with them regularly and have honest conversations, I think that's imperative to the relationship. Employer

She was going to leave, and that was probably about two months ago. It's been quite I think miraculous turnaround, in terms of how her work has improved. I wouldn't necessarily say it was anything that I did, I think it's just about opportunity, actually continue but offer you the opportunity to talk just outside of to deal with at work.
Employer

Employers interviewed noted that the first step in this process is asking the manager whether they feel comfortable and able to manage someone with schizophrenia, as this can be seen as going "above and beyond the normal role as a manager". This again may be more difficult in a smaller organisation. One employer spoke of spending a considerable amount of time providing support to an employee, discussing issues which many might argue fall beyond the remit of a manager.

I spent about two and a half hours, probably not something you would do on a regular basis, and she was very tearful, very distressed, actually talking about contemplating suicide. I am not a counsellor, but I've dealt with, I've had experience as a manager and I've dealt with lots of different types of people experiencing different forms of stress.
Employer

The blurring of the lines between work and non-work support may be an issue for managers, particularly where the issues are causing stress and impacting on the employee's ability to work.

She couldn't do that [her work] because she said she had too many other things going on in her life, including this appeal [regarding welfare benefits]. I then spent a bit more time talking to her about it and actually helped her. Employer

It is important to remember that not all the support can come from the employer, and other sources of support need to be in place.

I think it's about the support whilst they're at work, but also they need to have support as well for the bit of their life that is their private life however they manage to find it. It may not be the responsibility of the employer. Employer

What came through clearly in interviews with employers was the impact of low self esteem and low confidence on the ability of employees with schizophrenia to work.

You can see within that time the first I think three to four months her confidence was almost at rock bottom, and at one point she actually wanted to leave, because she felt like she couldn't actually do the job. It's almost all that enthusiasm and so on had been lost somehow in the first few months that she was with us. Employer

As arguably should be the case for all managers of people, a manager of someone with schizophrenia should be aware of the need to acknowledge and reward good work, and to reassure the individual that they are capable of working well. One employer interviewed noted the positive changes seen in their employee in response to being told they had passed their probation period. The importance of maintaining motivation and confidence was highlighted – in one example provided it was noted that despite having the experience, ability and potential to perform a role, the loss of motivation and enthusiasm could make work very difficult.

Another issue, raised by a person living with schizophrenia, was that it can be particularly difficult for someone with schizophrenia to raise concerns about work, and that they might even be taken advantage of.

I would avoid confrontation, I would avoid disagreeing with my boss or manager. I would always suffer in silence in a way, never had the guts to say look, you know OK, you don't think it's just right but look I've done this and I think we can work on this. So I've never had the guts to speak my mind and say look, I find the way you're speaking to me is

not... respectful. I'd rather you say this, this and this, but in a different tone because I think sometimes when people find that you're a sensitive person at work, some will just take advantage of that..... I think that's my idea of it – it could change. Lived experience

Access to support and advice for employers

Someone managing an employee with a severe mental health condition such as schizophrenia may need support and training themselves, to help them to provide appropriate support to staff. For managers in smaller organisations support options may be limited, particularly where there is no designated HR department or options to provide work cover. Larger organisations may have 'return to work' or rehabilitation or occupational health workers who may be able to provide support where someone is returning to work after an episode of illness, or to help people to manage their health on an on-going basis.

They [Occupational health specialists] have experience of dealing with a lot of the conditions. They take a lot of the time and effort required if you like away from us because obviously we're a client team, we can't manage every return to work. Employer

Employers may have to learn many things to be able to provide appropriate support for employees that need it. It is important therefore that employers are able to access support and advice to help them to do this.

Evidence suggests that employers would like receive more support. In 2009, 88 per cent of employers surveyed agreed that British industry needed more support to improve the way they deal with mental health in the workplace (rising from 76 per cent in 2006) (Brohan, Henderson, et al., 2010; Shaw Trust & Future Foundation, 2006).

I think employers need help as well, and maybe sometimes employers don't feel like they can ask for help, because they are made to feel like they are the experts and they should know how to deal with employees. Employer

Employers we interviewed had had to actively search for information to inform their understanding of the condition, what it entailed and how they might manage it. Getting the correct information is difficult, particularly given that schizophrenia is a diagnosis which covers a variety of potential symptoms and behaviours.

I did do some research on the internet but I needed more information about the individual and his specific symptoms, because I believe you don't get the same symptoms with every person. It's different for every person. Employer

A further barrier is the ability for people in an organisation to attend training and educational opportunities, due to limited availability of courses and, for smaller organisations, the inability to fund cover for the attending member of staff.

We have been offered some... reduced costs for first aid and mental health training and one of our members has been on it and another member is going to go on it. The problem is because they go for two separate days over two weeks, a lot of people are finding that quite hard to allocate the time. Employer

Employers will also have to deal with concerns about how to handle any health and safety concerns that other employees may have. This can be difficult to manage in practice, especially if an incident has already occurred. This was the case for one of the employers we interviewed.

It does make me rather nervous as an employee and as an HR consultant that if we get it wrong, he could still cause some serious damage to either property or to employees. And that does make me quite nervous. Employer

In such a rare case, employers would be recommended to seek assistance from external sources, including healthcare professionals to assess the situation and individual needs. Though this example was managed well by the employer, employers should be aware that they are not responsible for managing the mental health condition itself, and that access to other support services is sometimes necessary.

Input from healthcare professionals was valued by those we interviewed, and employers may need an avenue to seek advice from people with such expertise. One of our interview participants living with schizophrenia highlighted the value of occupational health support in particular as being helpful for them in terms of remaining in and being supported in work.

I think if people are more aware of mental health, and there's like the departments at work, that you know you can go and talk to for something, like for example to say look my boss is telling me this and I don't know how to deal with it, what do you think I should do? So to have advice at work, occupational health people that will be available, there and then, when you need to deal with a situation. I think that would be really helpful. Lived experience

Even these types of health and employment support workers may not have the specific knowledge and experience required to help support an employee with severe mental illness, however, and for some employers, being able to access some specialised, person-specific input is seen as valuable in terms of assessing abilities and needs.

What we do struggle with however is getting some proper assessment of employees with mental health conditions. We don't really have any specialists that can help us with giving us more informed information.... in terms of our occupational health providers, I don't believe that they really offered anything of value for assessments. Employer

The Individual Placement and Support (IPS) approach to supported employment (see section 4.3) provides some assistance to employers, particularly in terms of employees they have placed, by offering time-unlimited support to both employees and employers. The availability of support is less clear where a person with schizophrenia has not been employed through an IPS service or where they were employed prior to disclosure or diagnosis, and then require support to help them retain their role.

Some of our work with teams is around helping them understand, actually getting a job is great but we want people to sustain this job because a sustained job is the one that is going to lead to their long term mental health and wellbeing improving. Vocational Manager

For the employer to maybe go to other professional agencies who deal with schizophrenia, and support people with schizophrenia, and say "look I am facing this situation I don't know how to deal with it, I don't want to put my size 20 feet into it", and actually get some help. Employer

Though IPS services may be able to support by providing advice and training to those employers who seek it, the limited resources and variable availability nationally of IPS services mean that this is not always an option, and where the support does exist, it may not be sufficient.

I am not convinced that it was completely clear about what kind of support they could give to her post the commencement of employment. Employer

The most specific information, advice and support about a particular individual's needs, will likely come from that individual. What support is required, what triggers and stressors they have, and what flexibilities they need, will need to be discussed. Employers and employees should maintain an open dialogue. This might include agreeing on what they expect from one another. This can be seen as a two way process,

and the employee must also take some responsibility for themselves and their actions in response to reasonable adjustments and making certain allowances. In an example provided by one employer, in their management of an incident in the workplace occurring prior to disclosure, instead of taking disciplinary action the employer agreed to make reasonable adjustments to provide support for the employee, while the employee was also asked to agree to certain things, such as ensuring their compliance with medication and continuing to see healthcare professionals.

There was a responsibility taken on both sides so it wasn't just about what we can do for him but what he can do to help himself as well. Employer

3.6 Key points

- There is no single symptom picture for people with a diagnosis of schizophrenia. The nature and the extent of symptoms both vary greatly. Therefore it is important to consider the individual rather than just looking at the diagnosis.
- Positive or psychotic symptoms are usually well-managed. Negative and cognitive symptoms are much more common. It is these that are seen as having the greatest impact on ability to work.
- There has been a shift in thinking towards seeing recovery from mental illness not only in terms of recovery from symptoms (clinical recovery), but increasingly in terms of ability to lead a meaningful and satisfying life, including employment.
- Many people with schizophrenia are able to work, and willing to work. The benefits of working for these people are multiple, and include financial benefits, a sense of normality, increasing social contacts, increasing self-esteem, and providing a sense of purpose. Work is therefore thought to improve health and social outcomes, and is associated with improved quality of life.
- People with schizophrenia face many barriers to finding employment, as reflected in their very low employment rates.
- Arguably the greatest barrier is stigma, and consequent discrimination and self-stigma. Not only do misconceptions about people with schizophrenia's ability to work well and be good employees reduce opportunities for work, but also awareness of this conception leads to self-stigmatizing beliefs, which also impacts on motivation to seek employment. Stigma also prevents people from disclosing their condition, and thus impacts on their ability to access support.

- Other barriers include symptoms and side-effects of the medication, poor work history as caused by breaks in education and employment due to their condition, misconceptions about what types of jobs are suitable, and loss or feared loss of benefits through attempting to work. Poor management of physical health and monitoring of risk factors (particularly cardio-metabolic) has also been highlighted as a barrier.
- Even though healthcare workers are generally supportive of employment, work is rarely seen as a key priority for people with schizophrenia by their medical team.
- Employers also face barriers in terms of employing people with schizophrenia. Stigma and discrimination are important issues, which need to be addressed in order for employers to feel secure about employing someone with schizophrenia.
- Most employers do not know how to provide the support that an employee with schizophrenia needs – it can be seen as a lot to ask them to do. They need support and advice to develop supportive environments to facilitate disclosure, and allow them to provide the support and workplace adjustments that someone with schizophrenia may need to help them to remain in work.
- Some of this support and advice can come from the employee themselves. The maintenance of an open dialogue between the employer and employee as regards their needs is crucial for both parties.
- Many of the workplace factors that would help an employee with schizophrenia to stay in work are the same as in any psychologically healthy workplace – creating an environment in which we feel safe and support that is available for all those who need it.

So the impact of schizophrenia on people of working age can be very significant, especially if they wish to work. Indeed the barriers to employment are many and varied. Yet these barriers are not insurmountable. In the next chapter we explore the interventions which can help people living with schizophrenia to improve access to the labour market and to have fulfilling working lives.

4 What interventions are available for individuals with schizophrenia?

In this section we look at the interventions which are currently available for management of schizophrenia, the evidence of their effectiveness, the extent of their availability, and how they might impact on employment.

Pharmaceutical interventions are the most common interventions offered to people with schizophrenia. Alongside medication, other interventions are often used. In order of the most valued by practitioners, service users and their families (The Schizophrenia Commission, 2012), these are:

- Cognitive Behavioural Therapy (CBT).
- Peer support.
- Exercise prescriptions.
- Family Therapy.
- Creative therapies (art and music).
- Physical health checks.
- Self-help strategies.
- Complementary therapies.

These interventions and their relationship to employment are the main focus of this chapter. In its final report in November 2012, The Schizophrenia Commission noted that many people who prescribe and use these services do not feel that the mental health system in the UK empowers them to make decisions about what is best for them and their patients. A feeling of being disempowered by the mental health system was reported by 57 per cent of practitioners, 37 per cent of family members and 40 per cent of service users (The Schizophrenia Commission, 2012). This is likely to have an impact on service users and their practitioner's ability to use the mental health system to achieve non-traditional service goals, such as employment support.

Many interventions are delivered by Community Mental Health Teams (CMHT). Patients are referred to a CHMT by their GP, who will make a diagnosis. The CHMT provides a multi-disciplinary approach to managing individuals with complex needs. Team members come from a variety of different professions. This is likely include psychiatrists, community psychiatric nurses (consultant nurses), social workers, clinical psychologists, pharmacists, and a care coordinator (team manager). Other workers, such as psychotherapists, support workers, occupational therapists, and peer workers (those with experience of a mental health condition themselves) may also be on the team. They may also include Employment Specialists.

Those aged between 14 and 35 experiencing schizophrenia for the first time may be referred to a multi-disciplinary Early Intervention Team instead of CMHTs. They provide a time-limited service (around 3 years), and are often seen as taking a more holistic approach to care, incorporating educational and employment needs.

4.1 Pharmacological interventions: Antipsychotic medication

Pharmacological interventions in the form of antipsychotic medication are seen as the first line of treatment for schizophrenia (National Institute for Health and Clinical Excellence, 2010). By acting on neurotransmitters in the brain (dopamine and/or serotonin), they help control the experience of positive symptoms such as hallucinations, delusions and thought disorders. Antipsychotics are commonly seen as being effective at managing positive symptoms of schizophrenia (Velligan & Alphas, 2008), though less effective for negative symptoms for which only modest benefits have been found (Buckley & Stahl, 2007; Erhart, Marder, & Carpenter, 2006).

Antipsychotics are commonly divided into two classes – ‘first-generation’ or ‘typical’, and ‘second-generation’ or ‘atypical’. When first introduced, second-generation antipsychotics were thought to have higher efficacy, particularly for negative symptoms, and cause fewer side effects than first-generation antipsychotics. More recent evidence has made this less clear (Lieberman et al., 2005), and has cast doubt in particular on any link between atypical status and the impact on negative symptoms (Leucht et al., 2009). Due to the non-homogenous nature of the two classes of medication, it has been suggested that distinguishing antipsychotics as either first or second generation may not be valuable, and that decisions about which drug to prescribe should be individualised based on reactions and side effects (Leucht et al., 2009). Differences in drug response have also been identified in the use of oral and injectable medication (Kim et al., 2009).

The NICE guidelines provide limited guidance on which type of antipsychotic to prescribe, reflecting the individual nature of the condition. Oral medication is seen as the first option. The UK Psychiatric Pharmacy Group²³ offers further guidance suggesting that the type of oral antipsychotic prescribed in first episode patients, should be a first generation antipsychotic, except in special circumstances, e.g. where a patient experiences certain symptoms or side effects, in which case second generation may be considered.

NICE guidelines stress the importance of ensuring that the appropriate antipsychotic prescription is made as a result of a joint decision by the service user and healthcare professional. Where patients have an inadequate or no response to pharmacological or

23 <http://www.ukppg.org.uk/atypical-protocol-1.html>

psychological treatment, NICE guidelines recommend a review of diagnosis, dosage, medication duration, compliance with medication, engagement and use of psychological therapy and other possible causes of non-response. If patients continue not to respond, clozapine, which has a specific license for the treatment of this group of people, may be offered (National Institute for Health and Clinical Excellence, 2010).

Though dependent on the dosage and type of antipsychotic, as outlined above, many people experience significant benefits from using antipsychotic medication across a variety of areas. Evidence shows that antipsychotic drugs can reduce relapse of psychosis (Leucht et al., 2012), in the short term at least (van Os & Howes, 2012). Longer medication maintenance has been associated with being socially active, while lower medication maintenance has also been associated with higher symptom severity, treatment with mood stabilizers, and substance abuse (Haro et al., 2007). Antipsychotic medication has also been seen to provide some positive effects on some of the psychosocial disabilities that result from serious mental illness (Corrigan, Reinke, Landsberger, Charate, & Toombs, 2003) and cognitive function in early-stage of schizophrenia (Guo et al., 2011). The use of injectable medication has been shown to improve cognitive function, including verbal learning, memory and attention (Kim et al., 2009).

Though for some, the use of antipsychotics has resulted in the entire disappearance of positive symptoms, a more common outcome is a reduction in symptoms (Moncrieff, Cohen, & Mason, 2009) making them less intense and more manageable.²⁴ Antipsychotics are not effective for all people with a diagnosis of schizophrenia. Estimates of the proportion of people with schizophrenia helped by antipsychotic medication vary. The Royal College of Psychiatrists suggest about 4 in 5 people are helped by them,²⁵ while, as reflected in this interview, some estimates are less generous.

If we just say psychotic symptoms, I should think that probably at least about 50 per cent of people who have psychotic symptoms get a response to antipsychotics. Some will get rid of them entirely and some don't. But you then get people in that other group who have, if you like, manageable individual symptoms, while other people have rather unmanageable ones, and it's variable as to who that group is. Psychiatrist

²⁴ <http://www.rcpsych.ac.uk/mentalhealthinfo/treatments/antipsychoticmedication.aspx>

²⁵ <http://www.rcpsych.ac.uk/expertadvice/treatments/antipsychoticmedication.aspx>

In recent years, some doubts have been raised about the efficacy of antipsychotic medication (Lepping, Sambhi, Whittington, Lane, & Poole, 2011; A. P. Morrison, Hutton, Wardle, et al., 2012). Critics note that there is limited evidence for improved outcomes for those taking medication, while the implications of poly-pharmacy (the use of multiple medications by a given patient) and the side effects caused by antipsychotic use are more apparent (A. P. Morrison, Hutton, Wardle, et al., 2012). It has been suggested that the healthcare system has become over reliant on antipsychotic medication, and there is insufficient access to alternative options (Lepping et al., 2011; A. P. Morrison, Hutton, Wardle, et al., 2012).

We need a little less reliance on medication – we rely on it far too much I think – we should be thinking about all the other things that we can offer people, with medication just being one part of that. Lived experience

The length of time someone who has been prescribed antipsychotic medication for schizophrenia needs to remain on that medication has also been questioned, challenging the view that they should remain on it indefinitely. A recent longitudinal study identified that a significant minority of those who were seen as having better internal resources and greater resilience, were more likely to manage without the use of antipsychotics. Moreover, these individuals were less likely to be psychotic, experienced greater periods of recovery, and had fewer relapses (Harrow, Jobe, & Faull, 2012). This is supported by emerging evidence that, for some, symptoms might be manageable without any pharmaceutical intervention (A. P. Morrison, Hutton, Wardle, et al., 2012).

We need to look at other ways - talking therapies, anxiety management, psychosocial interventions, because as we know meds are not relevant for some people. We need to think about that, admit that. Expert with Lived experience

While all the healthcare professionals we interviewed were supportive of the use of pharmacological interventions, there did appear to be some disagreement as to the extent of their use, across different professions. For example, those working in Psychological disciplines appeared less certain than other colleagues.

There are some studies that show that people who are in the very acute stages of psychosis don't benefit as well from the psychological interventions as they might do from medication. However, medication doesn't work for everybody obviously. Nurse Consultant

Data from the National Audit on Schizophrenia implied that people with schizophrenia do not feel their views are taken into account in decisions about medication. Only 41 per cent of service users felt their views were taken into account; while 62 per cent of clinicians believed they did take service users views in board (Royal College of Psychiatrists, 2012). One possible explanation for this discrepancy, is that service users may not understand the information provided to them by clinicians, with only 62 per cent of service users feeling that the information they were provided on medication was in a form they could understand (Royal College of Psychiatrists, 2012). Low engagement with decision making regarding medication may be a concern for those who would like to return to or remain in employment, as medication can have impact on people's ability to work.

In the expert interviews, the message came across clearly that decisions on appropriate pharmaceutical interventions should be made based on the assessed needs and situation of the individual seeking treatment.

I think that probably has to do with where some of the cognitive function goes along with that. There are some people whose symptoms are controlled enough without medication, who are able to do that, and probably can function. I don't see those people but there is that end of the continuum and spectrum that will be out in the community, living their lives and getting on with their lives that I don't see. I see the other end.
Psychologist

Interviews with people with lived experience of schizophrenia showed that many value the role medication plays in the management of their illness.

Obviously the taking the medication has helped me I think, reduce the tensions and the confusion I feel, so it has been very, very helpful. Lived experience

Carer/family members we interviewed reiterated the importance of medication. Though for some there is concern that the person they care for had been reluctant to accept they needed to be on medication.

He thought that he was fine, he'd take it and then go you're fine, yes. I don't think he got it, he had to stay on it. He'll probably be on it forever, I think he's ashamed to be on it.. he didn't want to be on it. I think now he finally realized that he probably needs to be on it, maybe forever. Maybe not forever... Family Member

All those with lived experience we interviewed had received a pharmaceutical intervention. There was no evidence from the interviews that alternative options to medication were considered for these individuals (though other interventions are used

alongside medication). It is unclear whether they were given any option about taking medication for their condition, or whether alternatives are considered when someone does not wish to be on it.

Medication: An enabler for work?

The use of antipsychotic medication has been linked to improvements in health-related quality of life and vocational success when used continuously over a long period of time (Alonso et al., 2009; Corrigan et al., 2003).

The role of antipsychotic medication in controlling positive symptoms can impact positively on someone with schizophrenia's ability to engage in living normal life.

I certainly think some medications can help as well. We've had people who came to us very chaotic and distressed and unhappy, who were put on [antipsychotics] and are now operating independently and DJ-ing and doing all the stuff they wanted to do.

Psychologist

Avoiding episodes of psychosis is important in the workplace as in other areas of life, not only for the sake of the health, wellbeing and recovery of the individual, but also in terms of job retention. This was a clear message in the interviews – one employer explained how they had agreed with an employee that compliance with medication was a stipulation in the workplace agreement they had devised.

We just put a number of conditions on ... We basically said we want you to go regularly to your consultant because he hadn't seen his consultant for about 6 years. And we'll do annual reviews. We want confirmation in writing that he's been taking his medication because he also reduced his own medication. Employer

It is not clear however, if certain types of antipsychotic medication (specific drugs or between typical and atypical classifications) can be linked to better work outcomes or ability to learn and undertake job tasks (Kopelowicz, Liberman, Wallace, Aguirre, & Mintz, 2009; Resnick et al., 2008). Some research findings suggest that appropriate, highly structured skills training may have a greater influence on performance of some work tasks than antipsychotic medication (Kopelowicz et al., 2009). McGurk and Mueser (2004) also found that vocational rehabilitation might partially compensate for the impact of symptoms on work, and in particular highlighted that it is the severity of negative, not positive symptoms that most impact on work outcomes.

I think what I would say, and this is based on my own experience of working with people with these needs, is that if it's the view of the individual that medication is helpful to them, then it's likely to be very helpful in their search for work. In terms of helping them be in a place where they can look for work. But what I would not say, and I would challenge anyone who said this, is that somebody needed to be receiving or taking or compliant with medication before they could start looking for work. Vocational manager

Impact of Side Effects

A number of side effects have been associated with the use of antipsychotic medication. Clinicians making a decision about the type and dosage of antipsychotic medication to prescribe, have to weigh the extent of symptom reduction against the impact of side effects. Side effects vary in relation to which particular drug is used, the dosage, and the individual's response.^{26,27}

Side effects of antipsychotic medication can be considerable, and are seen as a primary reason for the high rates of discontinuation (Lieberman et al., 2005). Side effects associated with antipsychotics include: sedation, cognitive impairment, emotional flattening and loss of interest, stiffness and shakiness (similar to Parkinson's' disease), abnormal and persistent movement especially in the jaw, lips and tongue (tardive dyskinesia), sexual problems, and severe weight gain (Moncrieff et al., 2009).²⁸

He doesn't feel well in himself because he feels panicky all the time and he doesn't know how much is due to the long term effect of the medication because I think he's got, I don't know how you say it, tardive dyskinesia where his hands are wringing all the time and he's twitching. It must be horrendous because these drugs are powerful, and they do cause side effects, so you don't know how much is coming from the side effects of the medication making him unwell as well. Carer/Family member

In interviews with people with schizophrenia, higher dosages were associated with an inability to work due to the impact of side effects, particularly in terms of tiredness.

Before my meds used to make me really tired, I would take it and I would just be in bed for days, all day, I would just eat, bed, eat, bed. But now that I've reduced my meds, reducing has really had a big impact because I can do more things, I can be out there,

26 <https://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/schizophrenia/schizophrenia.aspx>

27 http://www.rethink.org/mental_health_shop/products/rethink_publications/only_the_best_medica.html

28 <http://www.rcpsych.ac.uk/mentalhealthinfo/treatments/antipsychoticmedication.aspx>

do education, you know, I can even go out. But before, I was really limited, I would take my meds and I'd be just sleeping throughout the whole day. I would hardly see outside. And then if I'm out, it can just seem like this girl, she's tired, she needs to sleep. But since they've reduced my meds. Lived experience

Research also indicates that some of the behaviours which affect work, often perceived to be negative symptoms of schizophrenia, may in fact be side effects of medication. van Os and Howes (2012) highlighted some rarely investigated side effects, as including persistent dysphoria and motivational impairment.

There's a huge overlap in terms of what is a side effect of the medication and what is the main symptom, they produce the same impact and it's very difficult to actually differentiate which is causing what. Psychologist

[Did your medication have any side effects?] Yeh, bad constipation, lack of concentration, forgetfulness, I think those were the main ones..... I maintained the medication for 10 years, I didn't stop. I had the symptoms all along. Lived experience

Reflecting the evidence that antipsychotic drugs are known to have a greater propensity to cause weight gain (National Institute for Health and Clinical Excellence, 2009), interviews also highlighted this as a significant side effect.

But there are also side effects such as weight gain which is a very common side effect of antipsychotic medication. And that in it self can lead to metabolic syndrome, diabetes, that type of thing. So it can lead to health problems which can impact upon work. Psychological therapist

Though not necessarily having a direct impact on ability to work, the long term implications of weight gain and obesity, in terms of increasing the risk of morbidity are a concern. Excessive body weight is the biggest risk factor for type II diabetes in schizophrenia (Connolly & Kelly, 2005) and antipsychotic medication is also linked to an increased risk of cardiovascular disease (A. P. Morrison, Hutton, Shiers, & Turkington, 2012). This is a particular concern given the evidence that cardio-metabolic risk factors may not be well monitored in people with schizophrenia (Royal College of Psychiatrists, 2012).

4.2 Psychological Therapy and Psychosocial Interventions

Psychological therapy and psychosocial interventions are often used alongside pharmacological interventions for the treatment and management of schizophrenia. This approach has gained momentum in recent years, with growing recognition of the importance of psychological processes in psychosis (as contributors to onset and persistence), as well as the need to address the limitations of pharmacological interventions (Lepping et al., 2011; National Institute for Health and Clinical Excellence, 2009). The inclusion of psychological therapy and psychosocial interventions in the NICE guidelines highlights their growing importance in contributing to symptom management and improving coping strategies as well as in mitigating the psychological impact of the condition.

The NICE guidelines (2009) review a number of different psychological therapies and psychosocial interventions for treating and managing schizophrenia. The guidelines recommend that both Cognitive Behavioural Therapy (CBT) and Family Interventions be offered to all people with schizophrenia. CBT has been identified as the most highly valued non-pharmaceutical intervention, favoured by 43 per cent of respondents in a study by the Schizophrenia Commission (2012), while family interventions were favoured by 20 per cent (though only 10 per cent of service users). NICE Guidelines also suggest that consideration be given to offering arts therapies. These were identified as the most valued intervention by 17 per cent of respondents. Experts interviewed in this study were also positive about the impact of such interventions, highlighting their value in terms of social functioning, problem solving, understanding and coping with their symptoms, and self-esteem.

The psychological interventions, they are helping people cope with positive symptoms and negative symptoms and what have interestingly found is that by helping people actually understand if they do have any kind of cognitive function deficits, understanding what that is about, and looking at ways to compensate, it has actually a remarkable effect on them. Psychologist

Despite the recommendations in the NICE guidelines and popular support for these interventions, the National Audit of Schizophrenia (2012) highlighted the variable nature of access to these services, finding that a third of service users in England and Wales did not offer any form of psychological therapy.

This may be addressed by the possible extension of the NHS Improving Access to Psychological Therapies (IAPT) programme. The IAPT currently supports the implementation of psychological interventions for people with depression and anxiety,

as outlined in the NICE Guidelines. "Demonstration sites" have recently been set up with the aim of extending this project to provide for increased service access for people with severe mental illness, including psychosis.²⁹

Cognitive Behavioural Therapy

Cognitive Behavioural Therapy (CBT) has been shown to improve both positive and negative symptoms of schizophrenia (Rector & Beck, 2001). It is identified that CBT is of particular use where symptoms have proven to be resistant to medication alone (A. K. Morrison, 2009).

You can help people deal with the positives, the hallucinations and delusions because there's a good literature on cognitive therapy for those types of symptoms.... a lot of people will have those to a greater or lesser degree as on-going symptoms, and what they'll find is they can find ways of self-managing those symptoms types. Psychiatrist

As highlighted in Morrison's (2009) summary of the literature on effectiveness of CBT, its use for the treatment of schizophrenia is increasing. Tai and Turkington's (2009) summary of CBT studies and reviews concludes that:

1. Randomized controlled trials (RCTs) have shown moderate effect sizes for positive and negative symptoms at the end of therapy and with sustained effects.
2. CBT has been effective in clinical as well as research settings.
3. Hallucinations and delusions respond to CBT.
4. Negative symptoms respond initially, and improvement remains at medium-term follow up.

The impact of CBT is variable, however. A review of the evidence found it to be less effective when people do not view themselves as having a mental health problem, have delusional symptoms, or have extreme primary negative symptoms. It is also less effective when people have comorbid disorders, such as substance misuse, because they are more difficult to engage and treat, though it is concluded that CBT does show promise even in these more complex clinical situations (Tai & Turkington, 2009).

Evidence also suggests that CBT can help improve job retention and improve levels of work performance for those with schizophrenia. Lysaker, Davis, Bryson, and Bell (2009) designed a CBT programme specifically to address low self-efficacy and self defeating

²⁹ <http://www.iapt.nhs.uk/smi/>

beliefs relating to employment, which can cause people with schizophrenia to leave employment. Participants in the programme were given a six month job placement. Those who undertook the CBT worked more hours, retained their jobs for longer, and showed higher levels of work performance than those that did not.

I think interventions such as CBT are particularly helpful because they really give the person the ability to be their own therapist and guide their own recovery. Nurse consultant

There is also emerging evidence that some people with schizophrenia may be able to manage their symptoms with only cognitive behavioural therapy, rather than in combination with antipsychotics. A study evaluating the effectiveness of CBT for people who had not taken antipsychotics for at least 6 months found that participants' experiences of hallucinations and delusions significantly reduced after a 9 month period of therapy (A. P. Morrison, Hutton, Wardle, et al., 2012). This suggests that therapeutic interventions have potential to be an alternative to pharmaceutical interventions.

Access to CBT was highlighted by the Schizophrenia Commission as a concern. Despite being recommended in the NICE guidelines (2009) for all people with schizophrenia, there is some doubt as to the extent of this in reality (A. P. Morrison, Hutton, Shiers, et al., 2012). As few as 1 in 10 people with schizophrenia who could benefit are currently getting true access to CBT (The Schizophrenia Commission, 2012).

Cognitive training / remediation

Cognitive training, or cognitive remediation therapy, is a tool to improve a variety of cognitive functions. This has particular implications for employment, as research indicates that it improves cognitive performance (Twamley, Jeste, & Lehman, 2003), including attention, working memory, cognitive flexibility, and planning for patients with schizophrenia (Bell, Zito, Greig, & Wexler, 2008). Cognitive training also improves functional outcomes, such as education and vocational function when combined with psychiatric rehabilitation (Bell et al., 2008; McGurk, Twamley, Sitzer, McHugo, & Mueser, 2007; Wykes, Huddy, Cellard, McGurk, & Czobor, 2011).

Studies combining various types of cognitive training interventions with vocational rehabilitation have found that this combined approach improves vocational outcomes. These included increased numbers of hours worked, higher income, higher employment rates and higher rates of competitive employment, than those who only undertook

vocational rehabilitation (Bell et al., 2008; McGurk, Mueser, & Pascaris, 2005; Vauth et al., 2005). However, further research is needed to see the persistence of these benefits and whether they impact on work outcomes (McGurk et al., 2007).

Family Interventions

The NICE Guidelines (2009) state that family interventions should be offered to families of people with schizophrenia where they live with or are in close contact with the person with schizophrenia, starting during the acute or later phases. Sessions are carried out on an on-going basis (at least ten planned sessions), lasting for at least 3 months. Interventions should have a specific supportive, educational or treatment function and include negotiated problem solving or crisis management (National Institute for Health and Clinical Excellence, 2010).

Family strategies attempt to reduce environmental stresses on people with mental illness, whilst promoting social functioning (Falloon, 2003). Psycho-educational family interventions, as an adjunct to medication, are thought to reduce the rate of relapse, improve symptomatic recovery, and enhance psychosocial and family outcomes (Dixon & Lehman, 1995; Murray-Swank & Dixon, 2004). Falloon (2003) categorises two family intervention strategies seen as particularly effective for people with schizophrenia. Firstly, carer-based stress management (derived from CBT) which aims to enhance the problem solving efficiency of the patient and his or her social support system and to actively promote the achievement of personal life goals, and secondly, educating caregivers in stress reduction strategies and increasing the acceptance of behaviour associated with both positive and negative symptoms.

In a survey reported by the Schizophrenia Commission, it was noted that although 20 per cent of all respondents (practitioners, service users and their families) found that family interventions were the most valued non-pharmaceutical interventions for them, only 10 per cent of service users gave this response (The Schizophrenia Commission, 2012).

Reflecting this finding, carers and family members we interviewed spoke most about the importance of this intervention.

[She] doesn't talk about her feelings and I think its one way she can be encouraged to do so, so I think, I don't know whether it will lead anywhere but we're quite interested really. Carer

Evidence of the impact of family interventions on employment outcomes is limited, however a Cochrane review of family interventions for schizophrenia (Pharoah, Mari, Rathbone, & Wong, 2010) suggested that it may reduce likelihood of relapse and hospitalisation, which in themselves may increase the likelihood that individuals will remain in or return to work.

4.3 Peer Support

Despite being seen as the second most important non-pharmaceutical intervention by practitioners, services users, and their families (34 per cent) (The Schizophrenia Commission, 2012), there is no formal provision for Peer Support in the NICE guidelines.³⁰ The role of peer support in delivering or contributing to mental health services in the UK has begun to develop following recent growth in the USA, Australia and New Zealand (Repper & Carter, 2011).

Taking a recovery-oriented approach, peer support uses the expertise of people with lived experience to help others build hope, self esteem and empowerment, in order to achieve their goals and aspirations. The literature shows that for the patient, the provision of peer support can lead to improvements in social support, reintegration into the community, reduced feelings of self-stigma and feelings of being understood. (Repper & Carter, 2011).

Socialising with other people with lived experience of schizophrenia who are at different stages of their recovery – role models, peers, peer support and stuff like that...half the difficulty is when people work it into their thinking like no one has done what I've done, its never been that hard for anybody else... there can always be a light shone in that dark tunnel that can produce a little bit of vision, and you only need a little bit of light at the end of the tunnel to make your way through. Expert with Lived experience

The value of peer support workers as part of the mental health team has been highlighted as valuable in the literature (Repper & Carter, 2011), and is a sentiment which was also found within our interviews.

If they hear peer support workers in teams talk about work they will engage more with the peer support worker – it happens all the time, I see it all the time. It helps if the peer support worker can have these enlightening conversations about anything that the service user does not understand. When the service user doesn't understand

³⁰ <http://www.nice.org.uk/nicemedia/live/11786/43608/43608.pdf>

he doesn't ask – when you are a peer support worker you can open up that area of conversation. Expert with Lived experience

I think we could be employing people with lived experiences of mental health themselves to set really good examples as an organisation that we are not just a mindful employer but that we also have a very positive plan of action about employing people who have experienced mental health problems including schizophrenia. Nurse consultant

It was evident from the interviews that peer support workers were not valued highly enough by the health system. Concerns have been raised in research that the way peer support workers are viewed by other healthcare professionals could impact on their status within a team, especially if working with people who used to treat them (Repper & Carter, 2011).

The thing that frustrates me is when I looked at how low paid they are, compared with other professionals. And yet actually, when they give such value to the team, but they just don't have the qualifications, it seems very unequal. Psychologist

There's a separation that always enforces that separation between them and us. Psychologist

For the person with schizophrenia employed as a peer support worker, there will also be benefits, As discussed elsewhere in this report, employment can mean benefits such as increased self-esteem and empowerment, and gaining a greater sense worth (Repper & Carter, 2011). However, the role does not come without hazards. Peer support workers have to learn how to manage the fine line of being a professional and yet a friend and managing professional boundaries. The risk of relapse and the effect on both parties is an issue that needs to be managed correctly so as to avoid loss of confidence. The success of such roles therefore is often dependent on the quality of support and training available (Repper & Carter, 2011).

4.4 Early Intervention for Psychosis

The importance of education, training and employment for young people with psychosis is internationally agreed - as clear from the Meaningful Lives Consensus statement (The International First Episode Vocational Recovery Group, 2010).

“This statement was created with the aim of elevating the place of functional recovery such that it is seen as being equally important with symptomatic recovery.” (The International First Episode Vocational Recovery Group, 2010)

This emphasis is based on the evidence of a link between longer periods of untreated psychosis and poorer outcomes (Loebel et al., 1992), and that it is the first three years of psychosis that represent a critical period in terms of recovery (Birchwood, Todd, & Jackson, 1998).

The idea was that the longer the people were left untreated the worse the outcomes and that was outcomes like medical outcomes, symptomatic outcomes, social outcomes, psychological, every single indicator was worse off if people were left. Psychologist

The Early Intervention in Psychosis (EIP) service model was developed in response to this. These services focus on younger people, given someone's first experience of psychosis often happens between the ages of 16 and 30.³¹ The model aims to reduce delays in treatment and management of early schizophrenia.

All interventions really should be timed as early as possible to either maintain people in employment or to get people working towards that as soon as possible. Psychological therapist

EIP services are seen as taking a more holistic approach than traditionally observed in CMHTs. Given the age group, the emphasis of treatment and recovery is on educational and vocational outcomes, as well as social and personal (Craig et al., 2004).

I think that's the difference between EIT and traditional services, I think traditional services ... a lot of people would disagree with this but I think often have focused on symptom reduction rather than personal goals of the individual. Psychologist

I think the emphasis is on getting people back to work or into education, or continuing education, whatever. I don't think, unfortunately, that other services have that philosophy and culture by and large. Psychologist

The importance of education and vocation in this model are emphasized as core features of the model. In a briefing document, the Centre for Mental Health state that: The young person should have a vocational assessment; The young person should be supported in employment, education or other valued occupations within normal environments; and, The achievement of normal social roles should be given the highest priority.³²

³¹ http://www.rethink.org/about_mental_illness/early_intervention/

³² http://www.centreformentalhealth.org.uk/pdfs/briefing_23.pdf

I think people who are working in early intervention and psychosis services and CAMHS³³ working with adolescents are probably geared up to think more about supporting people back into employment or education. Nurse Consultant

People will get medication and traditional approaches, but the idea is to keep medication to a minimum and to focus on getting persons back onto the normal life trajectory really, so getting back to college, seeing their friends, not getting into the whole identity of the 'mental health patient'. Psychologist

Work is one of the key issues within the EIT, I believe it should be. Psychologist

It [work/education/training] should be considered from day one. As in it should be within the original assessment. Psychologist

In the UK, Early Intervention Teams (EIT) provide services for people aged between 14 and 35, who are experiencing, or are at risk of experiencing their first episode of psychosis. They provide services for a limited period of time, usually around three years, before the service user goes back to primary care. The teams take a similar model to Community Mental Health Teams (CMHT), in that they are multidisciplinary, and treatment and management they offer includes both pharmaceutical and psychosocial interventions. Evidence however indicates that those receiving support through a EIP service are less likely to experience relapse, and positive symptoms are also reduced (Bird et al., 2010).

The effectiveness of EIP over "standard care" through a CHMT has been attributed to several factors, particularly the importance of capping case loads, to the end of allowing the provision of services tailored to individuals (including in terms of ensuring pharmaceutical interventions are appropriate), and providing more time for staff training, particularly with the aim of providing more psychosocial support (Bird et al., 2010; Brabban & Dodgson, 2010).

The importance of smaller case loads in terms of the provision of vocational support, in association with IPS services, was highlighted in our interviews:

As a manager I am becoming quite concerned if somebody's case load is over 25, and certainly if it's over 30 I want to sit down with that person and look at their case load and look at how we can manage that, help them manage it more effectively, because I

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think quality of service falls off once people are struggling with case loads of over 30.

Vocational Manager

Research also shows that service users are twice as likely to receive a psychosocial intervention in an EIT than in a CMHT (Bird et al., 2010). Looking at a particularly successful EIP service, Brabban and Dodgson (2010) identified a critical factor as being better staff training in psychosocial interventions (as seen in over 90 per cent of sampled EIP services in England (Brabban & Kelly, 2008)).

There was a clear message in the interviews that some of the factors that had proven to be effective in EIP services, should be applied to other mental health services.

I think there is a critical period that we should get to people within so that they are receiving the right messages about their mental health and recovery, which would be two huge factors in helping them to just get back on with their life. To get back into their education that they've stopped and missed or get back into their employment. I think other groups of patients, it's really difficult to say. I think there is a group of the new long stay patients who may struggle more to get into employment. But again I think it's about fitting the employment to them rather than trying to fit them into employment.

Nurse Consultant

The concern was raised that the factors which have made the EIP service model effective are being diluted, due to funding and other pressures: in particular the meshing of the EIT and CHMT.³⁴

What you're finding is people's caseloads are going up, it's no longer useful because it's literally just part of a CMHT now.... They're renaming CMHT to EIP teams without actually changing the model. Psychologist

A key issue identified in interviews was that it is difficult for someone to return to 'standard' services or primary care services after a period with the EIT, given the very different philosophies that guide them, particularly in terms of importance of and ability to work.

That's a big problem for a lot of people who've been through EIP, and that they've had a very psychosocial approach for three years and a recovery orientated approach and then after go to a traditional service and be told, oh you've got schizophrenia and that is for life, you know you can forget about your aspirations... Psychologist

³⁴ http://www.nhsconfed.org/Publications/Documents/early_interventionbriefing180511.pdf

The concern was also raised in interviews that despite the positive outcomes for those undergoing EIP, the expense involved has led to a reduction in services, rather than an expansion to incorporate the positive elements into standard or mainstream care. A further concern raised was that some trusts dilute the model, which reduces its impact.

Originally it came from the NHS plan, that was the idea was that every part of England needs to have an early intervention service.... at one point, I think, every trust had it's own service, so it was widespread across England. What interesting is that although EIP teams, were evidenced based, all mental health services the cost, you need to put in a lot of money upfront to get the outcomes, and the outcomes are people, things like fewer relapses, fewer hospital admissions, few suicides etc. Although they were getting significant savings with EIP teams...because they're expensive to set up, and the money has to go in upfront, a lot of trusts now across the country are starting to disband them, or dilute the model, which is really depressing. Psychologist

It has been argued that any cost savings in this way are short sighted, given the long term savings gained from using EIP service models, particularly in terms of employment outcomes, suicide reduction, and reduction in relapse and readmissions. In a report by the NHS Confederation it is concluded that comprehensive implementation of EIP in England could save up to £40 million a year.³⁵

4.5 Health and employment support policies

The health service is the gateway through which many of the most significant interventions, both medical and social, are delivered for people living with schizophrenia. The importance of employment for people with severe mental health conditions such as schizophrenia is explicit in the NHS Outcomes Framework 2013/14, with “*improved functional ability, through employment, in people mental illness*” as a specific outcome (The Department of Health, 2012b). This is very important to the future role of employment for those with mental illnesses, as from April 2013 the NHS Outcomes Framework will provide the basis for the government’s measurements of the effectiveness of the NHS Commissioning Board and Clinical Commissioning Groups (CCG) (The Department of Health, 2012a).

However, there are currently no specific outcomes relating to mental health and employment in the Clinical Commissioning Group Indicator Set or CCGIS, (formerly know as the Commissioning Outcomes Framework) the framework designed to guide and measure the outcomes of services commissioned by clinical commissioning groups

35 http://www.nhsconfed.org/Publications/Documents/early_interventionbriefing180511.pdf

(NHS Commissioning Board, 2012). This may yet change prior to the implementation of CCGs, due to occur by April 2013. However, if work outcomes remain excluded from the CCGIS there are concerns that there will be no incentive for CCGs to consider work as an outcome of treatment for people with severe mental illness.

Personal Budgets and the Care Programme Approach

The NHS provides support for helping patients into employment through a variety of different avenues. Someone with schizophrenia can, for example, access employment support through use of their Personal Budget. The personal budget has been part of a larger move within social care to provide a more personalised, patient-focused health service for people with long term conditions. The personal budget is designed to provide an eligible person with sufficient money to buy the services they need for their social care, and can either be a direct cash payment (albeit one that can only be spent on pre-agreed support interventions), managed and commissioned by the council, managed by a carer, friend or family member, or a mixture. It is highly flexible, and the size of the individual's budget and what types of services they may spend it on is decided between the individual and the Local Authority, with all decisions ultimately lying with the Local Authority.³⁶ Along with purchasing more traditional health and social care services such as a paid carer, this budget might be used to purchase services to assist with finding a job, this could include anything from hiring a job coach to covering the cost of a car to help get into work, or taking a course to learn new skills.³⁷

Signposting to support designed to help people into the labour market may also be available through the Care Programme Approach (CPA). The CPA is a method of coordinating care and is recommended in the NICE guidelines. It is used for those with severe or complex mental health needs who will require support from a number of different services (National Institute for Health and Clinical Excellence, 2009).³⁸ All people with a severe mental health condition should be offered a CPA based around the creation of a formal written care plan.³⁹ A CPA should include an assessment of all a service users needs, including in terms of employment, education and training.⁴⁰ The extent to which this occurs in practise however is unclear. The 2012 Community

36 'Personal Budgets in Social Care: a new way to arrange your care and support' (Age UK, Sept 2012, http://www.ageuk.org.uk/Documents/EN-GB/Information-guides/AgeUKIG26_personal_budgets_inf.pdf?dtrk=true)

37 'Mind Guide to Personal Budgets for Social Care' (Mind website, accessed 14th December 2012, http://www.mind.org.uk/help/social_factors/personal_budgets-the_mind_guide#benefits)

38 'MHMDS: Mental Health Minimum Dataset Online statistics 2003-11' (The NHS Information for Health and Social Care website, accessed January 2013, <http://www.mhmdsonline.ic.nhs.uk/>)

39 'Briefing: Housing and Mental Health' (Mental Health Network: NHS Confederation, Issue: 233, Dec 2011, http://www.nhsconfed.org/Publications/Documents/Housing_MH_021211.pdf)

40 http://www.centreformentalhealth.org.uk/pdfs/briefing_29.pdf

Mental Health Survey identified that many services users were not getting employment support. 34 per cent of respondents receiving care on CPA said that they would have liked support from someone in the NHS mental health service in finding or keeping work but had not received it. However, it is recognised that this may be an improvement, as for respondents who were not on the CPA this number rose to 51 per cent (Care Quality Commission, 2012).

Housing Policy

Any long-term health or social care provision for someone with a severe mental illness such as schizophrenia must be underpinned by policies designed to ensure stable, secure and appropriate housing. This was highlighted in the Coalition government's policy document '*No Health without Mental Health*' (HM Government & Department of Health, 2011). The kind of housing interventions and support that a person with a severe mental illness will receive varies depending on individual circumstances and the provision available in their local area. Supported housing, short-stay hostels, therapeutic communities, residential care homes and crisis houses are all accommodation options that might be available and suitable for different people depending on their individual circumstances and local provision.⁴¹

Having a settled and secure place to live is a key outcome of the Care Programme Approach (CPA), and is measurable through the Mental Health Minimum Dataset. The Community Mental Health Survey found that 27 per cent of people on a CPA wanted help in finding or keeping accommodation but had not received it. Whilst this figure could be improved, it is lower than those who were not on a CPA, where 49 per cent would like support in this area but had not received it (Care Quality Commission, 2012).

Support in the workplace

In recent years, a number of policy reviews, under both the current and previous government, have emphasised the importance of implementing and developing interventions to help people with physical or mental disabilities maintain their employment, and to prevent a short break from work turning into long-term unemployment. This conceptual shift towards emphasizing what people can do as opposed to what they can't do is illustrated by the introduction of the Statement of Fitness for Work,⁴² implemented following the Dame Carol Black Review into the Health of Britain's Working Age Population (2008). The Statement, also known as the 'the fit

41 'The Mind Guide to Housing and Health' (Mind, Accessed January 2013, http://www.mind.org.uk/mental_health_a-z/7975_the_mind_guide_to_housing_and_mental_health)

42 <http://www.dwp.gov.uk/healthcare-professional/news/statement-of-fitness-for-work.shtml>

note', is issued by GPs to patients after they have taken more than seven days off work ill. It aims to improve individuals' and employers' access to timely information about when and with what support and interventions they might return to work. By focusing on their abilities, people with health conditions are supported to stay in work or return to work more quickly, and so reduce sickness absence.

'Health at work: an independent review of sickness absence' (2011) produced by Dame Carol Black and David Frost built upon these ideas in the context of supporting employers. The government's response to this report in 2013, *'Fitness for work'* promised the creation of a Health and Work Assessment and Advisory Service. This service is intended to intervene once a person has been on sickness absence for longer than four weeks. The service will provide expert advice on the functional capability of the employee, assist employers in making relevant adjustments to the workplace, and signposting to other services for further interventions or treatment (Sickness Absence Review Response Steering Group, 2013). As this is a recent announcement many of the details of this intervention have not been confirmed, but it is expected that the service will be rolled out at some point in 2014. However, the 'job brokering' recommendations of the Black-Frost review have not been fully embraced and there are concerns that the online rather than face-to-face emphasis of the proposed service may not reach some 'client' groups effectively.

Current interventions aimed at supporting people with disabilities to remain in the workplace include Access to Work grants. Since 1994, Access to Work grants have been available to assist people to return to or remain in work by providing financial support to make adjustments to the workplace (Markham, 2004). These adjustments go beyond the 'reasonable adjustments' that employers are legally required to implement under the Equality Act 2010.⁴³ The grant is available to people over 16 with a disability, health or mental health condition, and covers adjustments such as special aids and equipment, support workers (ranging from travel buddies to job coaches to translators), travel to work, travel within work and communicator support at the interview. The implementation of the Access to Work scheme is commissioned to external contractors. Provision is highly flexible, and is agreed upon by the individual, the employer and the Access to Work provider. The cost of providing these adjustments is shared between the government and the employer, up to a threshold of £10,000, beyond which the

43 'Operational Changes to Access to Work' (Department for Work and Pensions, December 2010, <http://www.dwp.gov.uk/docs/access-to-work-operational-changes.pdf>)

government will cover the full cost.⁴⁴ Moreover, the proportion of the costs falling on the employer depends on the organisation size, with the government contributing the entire cost in the case of organisations with fewer than 50 employees.⁴⁵

Unfortunately, Access to Work has a relatively low rate of take up by people with a mental illness. Between April and June 2012, only 500 people who reported mental health problem as their primary medical condition received an Access to Work grant, out of a total 20,400 grants.⁴⁶ There is currently no data available on how those with a mental health condition use the Access to Work grant, but the most common uses are payment for support workers and travel to work.⁴⁷

A reason for the low usage is thought to be due to low awareness of the Access to Work grants among both employers and people with mental health issues. The current government announced in November 2012 an intention to address this, stating that they hope to see the grants as not only helping those with mental health issues enter or return to the workplace, but as encouraging the idea that having a mental health condition is not necessarily an insurmountable barrier to work.

Department for Work and Pensions back to work support

A number of government interventions are directly aimed at encouraging and supporting people with disabilities, including severe mental health conditions, back into work. The most notable of these are the Work Programme and the significantly smaller but more specialist Work Choice scheme (for more on these scheme, please refer to section 3.4). Whether an individual is referred to these schemes depends on several factors, including benefit type, the desires of the individual, and the judgement of a JobCentre Plus Advisor or a Disability Employment Advisor.⁴⁸

44 'Employers guide to Access to Work' (The Department for Work and Pensions, 2012, <http://www.dwp.gov.uk/docs/employer-guide-atw.pdf>)

45 Esther McVey, 'Written Ministerial Statement: Access to Work' (The Department for Work and Pensions, 19th November 2012, http://www.parliament.uk/documents/commons-vote-office/November_2012/19-11-12/9-DWP-AccessstoWork.pdf)

46 'Access to work: Official Statistics' (Department for Work and Pensions, October 2012 <http://statistics.dwp.gov.uk/asd/workingage/atw/atw1012.pdf>)

47 Ibid

48 'Employment and Support Allowance claimant journey: Stakeholder information pack' (Department for work and Pensions, November 2012, <http://www.dwp.gov.uk/docs/esa-stakeholder-information-pack.pdf>)

If a person is not referred, or does not volunteer for, either of these schemes they may access back to work support through JobCentre Plus. This support can include job brokering, Next Step skills training, work experience, sector-based work academies and help with moving into self-employment.⁴⁹

4.6 Vocational Rehabilitation and Supported Employment

Vocational rehabilitation is an idea and an approach as much as an intervention or a service. It is defined as: “*whatever helps someone with a health problem to stay at, return to and remain in work*” (Waddell, Burton, & Kendall, 2008).

The conceptual role of employment as part of recovery and how it impacts an individual’s health has important implications for how vocational rehabilitation has been, and is currently, delivered. What constitutes ‘work’ in terms of approaches to vocational rehabilitation has been subject to considerable debate. This involves consideration of what factors are fundamental in terms of facilitating the recovery and improving health and wellbeing of those with severe mental health conditions. For example, how much is being occupied and having a daily structure useful, or must the focus be on attaining a paid job? If so, does pre-vocational training help people to find a job? What are the relevant benefits and disadvantages of undertaking voluntary or sheltered employment, or short-term placements, in social enterprise operations, as opposed to finding competitive, paid work, in integrated settings (i.e. those where people without mental health conditions also work). Bachrach (2000) argues that a broad definition of ‘work’ subsuming a variety paid employment, pre-vocational and non-vocational options might be useful given the differences in interests, skills, talents, physical abilities and limitations of the condition.

‘Supported Employment’ and ‘Pre-vocational Training’ are the two vocational rehabilitation models which have been commonly applied to people with schizophrenia and other severe mental illnesses. They can be briefly described as (Centre for Mental Health, Department of Health, et al., 2012; Corrigan & McCracken, 2005; Crowther, Marshall, Bond, & Huxley, 2001a):

Pre-vocational Training, or “Train then Place”: Training and development to prepare an individual prior to seeking competitive employment. This includes training in general skills (such as formal and informal rules) for the working environment, and handling “real-world” demands. This is seen as reflective of the ‘medical model’ of rehabilitation (Corrigan & McCracken, 2005). This may also include volunteer

49 Ibid

placements and sheltered work before competitive employment (Twamley et al., 2003).

Supported Employment, or "Place then Train": Focus is on getting people into competitive employment first (as quickly as possible), followed by training and support on the job, i.e. teaching people the skills they need for their immediate environment (Corrigan, Steiner, McCracken, Blaser, & Barr, 2001). It has been suggested this approach may be less about achieving economic self-sufficiency, but rather as a form of treatment (Glynn, 2003), and it is seen as more of a social work approach to rehabilitation (Corrigan & McCracken, 2005). The most well known model of Supported Employment is Individual Placement and Support (see below).

Evidence suggests that "train then place" models do not have a high success rate in placing people into competitive employment, despite the fairly widespread use of this model (Burns et al., 2007). This reflects the situation for addressing unemployment in the broader population (Daguerre & Etherington, 2009).

Sheltered employment models used to be a common approach to vocational rehabilitation for people with severe mental health conditions. In such models, people with disabilities are employed exclusively (or primarily) in an organisation, with the expectation that the experience will prepare them for moving into open employment. Social Firms or Social Enterprises are seen as the modern development of sheltered models, taking a more socially inclusive approach and providing higher quality work and employment. Here disabled and non-disabled people work together, with an emphasis on the participation of all employees in all aspects of the enterprise, including management, to the end of creating a successful business that can support paid employment (Boardman, 2003).

There is clear evidence however that this has not been effective, and that sheltered employment and sheltered work schemes do not lead to open employment (Rinaldi et al., 2008). Evidence from our expert interviews also did not support the use of pre-vocational models:

I'm very critical of rather expensive efforts made with people with schizophrenia on work which seem to be totally misguided, like sending them on endless training courses... As opposed to putting them into one to one contact with someone who could employ them. Carer/Family member

There is good evidence that traditional step-wise structured rehabilitation, sort of Boston model, doesn't get them into work. So to some extent the idea that people with schizophrenia learn the tasks and then cope with sheltered work and then go into open employment, I think the evidence is fairly strongly against it. Academic Psychiatrist

One of the major criticisms levied at pre-vocational rehabilitation is that clients are not retained for long enough in the 'continuum of care' to support their placement in appropriate jobs (Twamley et al., 2003).

It's the step of getting into work that matters, and you don't usually get progression after that. Academic Psychiatrist

This is something addressed in supported employment models, which are seen as a more effective method of getting people with severe mental health conditions into competitive employment. This shift is supported by the evidence. A systematic review on behalf of the Cochrane Collaboration (Crowther, Marshall, Bond, & Huxley, 2001b) found that people who received Supported Employment were significantly more likely to be in competitive employment than those who received Pre-vocational Training (at 12 months 34 per cent were employed in Supported Employment compared with 12 per cent in pre-vocational training). Further the authors concluded that there is no clear evidence that pre-vocational training was any more effective than standard community care.

Evidence suggests that that people with schizophrenia are more likely to work competitively when receiving evidence-based supported employment services (Cook et al., 2008), and that supported employment models are more effective regardless of poor work history (Bond et al., 2001). Though it is noted that outcomes for people with schizophrenia undergoing supported employment are often worse than those for people with other severe mental health problems (Wewiorski & Fabian, 2004), there is increasingly evidence that use of this model can lead to better outcomes for people with schizophrenia than seen for their counterparts with other severe mental illness diagnoses (Cook et al., 2008).

One example of the way supported employment can be used effectively is the User Employment Programme, implemented at some UK NHS trusts (see box below). Here, personal experience of a mental health condition is seen as a desirable or essential qualification for employment. People with mental health problems are employed in existing posts on the same terms and conditions as other employees, with a programme of support for those who need it is built into the normal employment practices (Boardman, 2003).

Case Study: Carpet Cleaning Care

[Carpet Cleaning Care](#) is a supported employment project based in South London. Established in 1994 it aims to provide a professional cleaning service to its customers but also an opportunity for paid employment and training for people with severe mental illnesses.

The carpet cleaning project was established with a grant of £1.5k as an attempt to provide employment opportunities for service users leaving institutional care. Over a 10-year period, the project went on to become a 'Beacon' service, winning numerous national awards, and has been showcased by a large charity as an example of innovation in practice. By 2003 the project had been granted £137k to explore and research its transformation and expansion. A key aim of the expansion of the project was that the workers might gain power, control and confidence and the business would be a success, enabling some workers to take the choice to earn enough to possibly come off benefits.

According to research undertaken between 2002 and 2004, by Mark Bertram the Vocational Development Manager at Carpet Cleaning Care, the company expanded from 7 to 13 employees, and was able to cover 57 per cent of its running costs and anticipated an increase in profits.

As part of the evaluation of the success of the project a customer survey was conducted. This generated very positive results, with the quality of the work was rated consistently high and all the customers were happy to recommend the service to others. In addition, a survey was conducted of referrers – those who had referred service users to the project – in order to collect views about the perceived impact of participation of the service users on their health and wellbeing. Again, the responses were positive:

"It has helped [client] structure her week around meaningful activities and earn some money in the process. Level of self confidence is higher."

"It has helped [client] to provide direction and purpose to his daily activity. He feels he has gained a whole range of skills being involved."

"I think it is an ideal project for [client] at this time. I value the carpet cleaning crew because it offers real employment and pay to some of the most excluded members"

of society. I believe it has increased [client's] sense of wellbeing and engagement with services generally."

In a service user survey, the reflections of employees were also collated. As one said:

"I think that it is more possible to work, pay bills, keep on the straight and narrow than it is on benefits. I think that if one has work in society they get a lot more respect".

The company's journey has been complex and not without setback. However, it is now operating within the South London and Maudsley NHS Foundation Trust (SLAM) as a registered charity and ploughs its surpluses back into its operations.

Source: <http://www.socialfirmsuk.co.uk/resources/library/carpet-cleaning-care-research-dissertation>

Individual Placement and Support (IPS)

When they do wish to return to work, there is a large a body of evidence around IPS - it helps them get to work. Academic Psychiatrist

On current evidence, IPS is the most effective method of helping people with severe mental health conditions who want to work, to achieve sustainable competitive employment (Bond, Drake, & Becker, 2008; Burns et al., 2007; Rinaldi et al., 2008).

The emphasis of the IPS model is on an employment specialist working closely with an individual to understand their individual strengths and weaknesses and find a good job match for their individual abilities and skills (Glynn, 2003). The eight principles of IPS are (Sainsbury Centre for Mental Health, 2009):

1. Competitive employment is the primary goal;
2. Everyone who wants it is eligible for employment support;
3. Job search is consistent with individual preferences;
4. Job search is rapid: beginning within one month;
5. Employment specialists and clinical teams work and are located together;
6. Employment specialists develop relationships with employers based upon a person's work preferences;

7. Support is time-unlimited and individualised to both the employer and the employee;
8. Welfare benefits counselling supports the person through the transition from benefits to work.

IPS has been extensively researched and has a good evidence base in the US and Europe from Randomized Controlled Trials (RCTs), considered the gold standard in research, in which a cohort of similar people are randomly assigned to one intervention or a control group to measure the impact of the intervention on outcomes. A systematic review of RCTs (Bond et al., 2008) which compared IPS with a control (usually treatment as usual or alternative vocational models) identified that on average 61 per cent of those in the IPS intervention group found competitive employment compared to 23 per cent in controls. The IPS group also found employment quicker, retained it for longer, and worked more hours per week. A large scale cross-European RCT by the EQOLISE (Enhancing the Quality of Life and Independence of Persons Disabled by Severe Mental Illness through Supported Employment) group, found IPS to be more effective than the best locally available alternative vocational rehabilitation service for every vocational outcome they measured. These included working more hours, working more days, more employed for at least one day, lower drop out rates, and lower hospital readmission rates (Burns et al., 2007).

In this respect IPS is seen to counter the difficulties that someone with schizophrenia might have learning new skills, as the emphasis is placed on finding a role based on their existing skills and experience, along with finding an employer who is happy to take them on.

Particular emphasis is placed on the role of IPS in promoting social inclusion for those with severe mental health conditions, suggesting it may fare better in this regard than some more common interventions.

A lot has been invested in IAPT and CBT but IPS is better, it promotes social inclusion, and it needs better promotion nationally. Occupational Therapist

Our interviews also found IPS services to be highly valued by service users.

They [employment support services] have given me guidance, they've give me support and they've provided the facilities as well as to help me look for employment and also they have assured me that I can do, they have given me that "can do" attitude which I apply. Lived experience

In the UK, IPS programmes are often integrated with Community Mental Health Teams (CMHT). For example, the implementation and integration of IPS into eight CMHTs in two London boroughs appeared to lead to an increase in the number of clients (a third of whom had a diagnosis of schizophrenia) supported to achieve vocational or educational outcomes. Outcomes included maintaining or obtaining open employment, voluntary work and entering mainstream education (Rinaldi & Perkins, 2007). Many IPS services are associated with other interventions, accessed through the CMHT and the NHS trust. This evaluation evidence shows that it is important to be clear that any supporting services must be evidence-based in leading to improved competitive work outcomes, and not detract from the principles outlined under IPS. They must be time-limited, and keep participants on the pathway to open employment.

Ensuring IPS services are well integrated with mental health services has been identified as critical to the implementation of IPS services (Drake & Bond, 2008; Howard et al., 2010). The co-location of services was highlighted in an interview as being particularly important to ensuring a good service for users. For example, co-location with the IAPT service and joint-programme development with them can be invaluable.

Integration of IPS with early intervention services is also seen as valuable for ensuring that young people, on the cusp of independent living, are not excluded from education or employment at this critical time. Rinaldi et al. (2004) looked at the impact of integrating IPS into an early intervention service on the vocational and educational outcomes of 40 patients (35 of which had a diagnosis of schizophrenia). Working as part of the multidisciplinary clinical team, a vocational specialist supported patients to find and keep jobs, resulting in an increased employment rate amongst these patients, from 10 per cent to 28 per cent after 6 months. After 12 months the proportion of patients who were not involved in any form of work or education had decreased from 65 per cent to 5 per cent.

There's been a period within mental health services within the NHS over the last ten or twelve years where there's been huge amount of work put in to build up high quality services. I think, I am thinking services with Somerset Partnership particularly, a part of that has been about early intervention psychosis. We work very closely with the team here, the early intervention team, to help people with work issues. I think what I'd say it would be heart breaking to see all that wound back, because of a lack of funding.
Vocational Manager

The role of Employment Support Specialists and Occupational Therapists

Having dedicated employment support specialists (ESS) (also known as employment consultants and employment support workers) is widely regarded as essential for the successful implementation of IPS (O'Brien, Price, Burns, & Perkins, 2003). The role of the Occupational Therapist (OT) is also seen as important. The traditional role of an OT in the CHMT is focused on the day-to-day life of their patients, helping them gain social and practical skills to help them within social, leisure and vocational settings. Although historically they have focused on in-patient care, in recent years there has been a move towards OTs working with out-patients as well. This work varies, and can include them working directly with employers and even training them about the special requirements of those they are trying to help. OTs may be employed by a health authority, a social services department or a voluntary organisation. OTs also often have a role with employers, with many having internal or outsourced OT consultants.

Howard et al. (2010) highlighted evidence that where new staff are employed to set up IPS programmes, enthusiasm for, and commitment to, the role is much higher. Rinaldi and Perkins (2007) looked specifically at outcomes when IPS services were led by Occupational Therapists (OTs), in a modified role, against having dedicated ESS. Though employment and education outcomes were improved when an OT took on the role, the results were far greater with a dedicated ESS.

There needs to be a person whose job and bonus, performance, is measured by getting my daughter into work, and who is sufficiently confident themselves, and senior enough to engage with employers. Family member/carer

The role of the ESS in this context is three-fold (Rinaldi & Perkins, 2007).

- 1. Working directly with clients as case managers:** including client engagement, vocational needs assessment, proactively assisting to gain employment/education, providing welfare benefits advice, assisting to gain additional support such as reasonable adjustments.
- 2. Working indirectly with care coordinators (in the CMHT):** including providing information, advice and guidance on vocational support needs, coordinate vocational plans with CMHT members, ensure priority is given to vocational goals in the CHMT.

- 3. Working directly with employers and employment /training services and agencies:** providing support for and developing links with employers, and developing links with services such as Jobcentre Plus, employment agencies, Connexions, colleges, other mainstream training providers, and other specialist employment/ training services for people with mental health conditions.

In our interviews, a wide range of suggested and anticipated roles were identified for ESS in terms of providing support for clients. There was an expectation that support would be quite holistic, including not only employment-centred roles, such as interview coaching, disclosure decision support, and preparing for reasonable adjustments conversation; but also more social and personal support, such as the assisting with managing routines, using internet banking, dressing for interviews, and support to attend interviews (i.e. making referrals to and liaising with local financial support organisations).

The social stuff is about making sure that they've got the networks, the social support, and the social things in place that we all take for granted... Nurse Consultant

The employer-facing aspect of the ESS role can be critical. One interviewee highlighted that part of the role is ensuring that employers are receptive to the clients needs before the opportunity to work is broached with the client. Other important aspects of the role have been identified as building relationships with employers, and ensuring they are adopting approaches which meet employers' needs (Shepherd et al., 2012).

As identified in our interviews with people with schizophrenia, the role of the ESS in terms of employer engagement can vary greatly depending on the needs of the employee. For some, the ESS does not need to broker the role with the employer, and some people with schizophrenia are happy to and able to approach employers and find work for themselves, with the ESS providing them support as they do. For others, the ESS was relied on to a far greater extent, with contacting the ESS being the first port of call when faced with any difficulties with employers or work. Again, it is important to keep in mind that different people will have different needs and require different levels of support.

There are some people who say to be honest I am good at getting jobs, I can get interviews, I am happy with that, we're talking about the interview for them. So it's about interview coaching. What we have I suppose.. it's fair to say the sort of continuum of interventions, and it's judgment with the individual we're working with about where do we engage with them and where do we engage with employers. Vocational Manager

It is the on-going support element of the ESS role (as stated in the IPS principles) that was highlighted as especially important. This applies to providing support for new employees, and in helping employees to maintain their role, for example, where a current employee has experienced a downturn in their condition.

It then led to high rates of job loss for people who had lost jobs they enjoyed for want of an intervention, job attention intervention, people were falling out of work as a consequence of their involvement with the mental health service. Vocational Manager

Without additional support, this situation would often mean the employee would leave their job to focus on their health and wellbeing, whereas with an ESS providing support to both the employee and the employer, there is a higher chance of job retention, even though it is argued by some that services may be less able to give support in terms of retention.

There is a debate to be had about whether one team can be doing both job retention, helping people who already have a job keep a job, and the job search through IPS. I think from [my] point of view is that it is actually a different skill set for both tasks. Vocational Manager

ESS are also seen by some as offering more continuity for patients, given the high levels of movement with health services. This is seen as important in terms of maintaining focus and goals, as well as in terms of managing symptoms.

Though the ESS role can be seen quite broadly, the responsibility for the employee's mental healthcare was positioned clearly with other members of the mental healthcare team.

I think other members of the team would be really important in terms of helping the person to be psychologically well enough to be able to go for those jobs. Nurse Consultant

There is some evidence that ESS are not always valued or given a voice within the CMHT. Responding to this evidence, Shepherd et al. (2012) emphasised the importance of an ESS having strong interpersonal skills and being persistent. Co-location of the ESS with other team members, attendance at key clinical meetings, and having the support of team leader were also thought to impact. In our interviews, ESS were positive about being increasingly included in the CHMT.

We do go to CPA's, but I think most of the dialogue is informal in a sense that it's about having a very open door, sitting alongside mental health colleagues, being very positive about what we do, delivering results where people can see, they can see the difference of people going to work. Vocational Manager

I think more so. More and more so really because over the year, we've been doing this for quite some time now and obviously, they've referred the individuals to us who've moved through that process, got into work and they've seen the benefits. They can clearly see the concrete benefits that come out of this that help people progress. So that's why they continue to refer appropriate individuals to us. If that process didn't work, then quite clearly they wouldn't refer people to us because it's as simple as that in real terms. Employment Worker

ESS can also have an important role in raising awareness in the CHMT, EIT or more broadly about the importance of vocational rehabilitation and what support employment can offer. This will have the dual role of increasing the awareness of health professionals of what the ESS role is and what they are doing, as well as generally highlighting the benefits of work for people with schizophrenia, and why it should be seen as an outcome, and what the barriers to work are for them.

Given this positioning, the OT is often seen along with the ESS (where present) as the 'vocational champion', taking a lead in the promotion of vocational services within the CMHT, and consequently addressing the negative attitudes sometimes associated with some health professionals that can present a barrier to employment for people with schizophrenia (Priest & Bones, 2012). OTs are seen as providing clinical support and advice to the ESS, educating and supporting other team members in considering vocational issues, and undertaking brief interventions for service users (Priest & Bones, 2012).

“Employment is everyone’s business.” – Training on Employment for Healthcare Professionals. A case study.

In 2010 Southdown Supported Employment in association with the Sussex Partnership NHS Foundation Trust began a training initiative to increase awareness amongst clinical staff about the importance of discussing employment with clients as part of recovery.

The “*Let’s talk about work*” training arose from a need to improve the implementation of IPS in Sussex . Although Employment Specialists were embedded within community mental health teams, it was found that an understanding of their role was mixed. Likewise, despite clinicians acknowledging the importance of employment in recovery, this was not reflected in their every day practice.

Employment Specialists and Vocational Champions delivered a 3 hour training session to their teams. Training included:

- Barriers to employment for clients
- Dispelling myths about barriers to employment
- Hints and tips on how to begin and manage conversations about work including client concerns about disclosure and benefits.

In-house training enabled trainers to tailor the material to the particular needs of their team. Training sessions provided adequate time for people to challenge their perceptions about employment and explore any prejudices they may have.

As a result of the training, referrals for clients wanting paid work increased. Clinicians felt more able to ask about employment and had surprising responses from some clients who had not previously expressed an interest in paid work. A shift towards paid work as an option for clients was also evident.

“We used to view voluntary work or education as a first step but not any more, now we think about employment.” Community psychiatric nurse, Sussex

Problems with the implementation of the IPS model

Despite all the strong evidence of the effectiveness of IPS for improving employment outcomes for people with schizophrenia, it is not currently widely, or well, implemented into routine clinical practice (Rinaldi et al., 2008) and there is no national approach to the implementation of IPS services.

If you look at the bigger picture, it’s a struggle. Lots of people with mental health issues are not getting into work. We’re being successful but you look at what else is happening elsewhere, it’s not so good. And we’re tiny, we’re very aware of our impact. We might be doing well but in the bigger picture, how much real effect are we having? It’s tiny.
Vocational Manager

It's all about making sure that every patient has access to specialist services that can help them get into work. Occupational Therapist

Concerns were raised in the interviews about the difficulty of integrating IPS into normal practice. This may also take on the guise of low support among other members of the healthcare team who may be sceptical of the value of the intervention (Shepherd et al., 2012), fear that it will lead to relapse (Rinaldi, Miller, & Perkins, 2010), or the belief that all symptoms need to be addressed before any progress can be made (Shepherd et al., 2012).

The SWAN – Supported Work and Needs study⁵⁰ – in South London was raised by several participants as highlighting the problems with implementation of the model in the UK. In this study, despite services receiving a 'good' rating on the scale, employment outcomes were poor, considerably more so than seen in studies of similar services (Howard et al., 2010). It has been suggested that this was due to misinterpretation of the IPS principles. A particular concern, highlighted by the study by Howard et al. (2010), as well as being raised in our interviews, was the low level of contact between IPS staff and clients. Given the high fidelity scoring for IPS in the UK (Rinaldi et al., 2008), the concern has been raised that there is a disconnect between the intention of the scale, and how it is interpreted, which consequently impacts on the implementation of IPS services.

Current investment in supported employment services is insufficient. Even where services do exist, there may be problems with implementation given the lack of support.

Over the past few years I've worked with a variety of really good non-statutory services, voluntary services, that I've been quite impressed with in terms of helping people get back to work. But over the past few years, funding has been cut and services have been closed. And I just think it's so short sighted in terms of getting people with psychosis back to work. Psychological Therapist

The broader implications of the poor economic conditions in the UK also influence poor implementation of the service (Rinaldi et al., 2010), particularly considering the evidence in Europe that local unemployment rates do impact on the effectiveness of IPS (Burns & Catty, 2008). The influence of this context has contributed to a more general failure to provide the support that we know works. Rinaldi et al. (2010) describes a situation wherein employment is not seen as a priority for health services; people with long term mental health conditions are not seen as a priority for government funded employment services; and, employment is not seen as a realistic outcome for people with severe mental health conditions.

50 <http://www.controlled-trials.com/ISRCTN96677673/SWAN>

Several participants of our study called for greater support for the IPS programme nationally. This reflects the consensus of support for IPS found among both researchers and practitioners in the US (Evans & Bond, 2008).

It's not about spending more money on services - it's making the most of them.

Occupational Therapist

There is no doubt that the IPS model, when implemented properly, is the most effective available model for helping people with schizophrenia to find competitive employment. This does not mean however that we should not continue looking at ways to improve these services, or to seek better models which might lead to higher rates of people with schizophrenia finding competitive employment (e.g. better incentives for employers).

4.7 Key points

- There are many interventions available which have implications for people with schizophrenia getting into, or remaining in employment. Interventions are delivered through a multi-disciplinary Community Mental Health Team (CMHT) or Early Intervention Team (EIT).
- Pharmacological interventions are the first line of treatment. Their primary value is managing the positive (psychosis) symptoms of schizophrenia. As medication significantly reduces of positive symptoms for some people with schizophrenia, it can enhance return to work and job retention. The side effects of antipsychotics, however, can be substantial and have impact on employment.
- Psychological therapies, particularly CBT, are valuable in managing both positive and negative symptoms of schizophrenia. They are usually used alongside pharmaceutical interventions. Psychological therapies are popular with patients, and their use is supported in the NICE guidelines, though access to services is limited. Psychological therapies are seen as particularly important in terms of employment.
- Family Interventions provide valuable support for family members as well as people with schizophrenia, to increase understanding of the conditions, as well as each other's needs and desires, and how they can help each other to achieve them.

- Peer Support workers are a source of motivation and support for people with schizophrenia, giving them a positive example of what they can achieve, and letting them know that they are not alone. Reciprocal benefits have also been found for the worker themselves, as their employment in their role enhances their sense of wellbeing and self-esteem.
- The Early Intervention for Psychosis service model focuses on younger people (e.g. 14-30) who are experiencing psychosis for the first time. The model seeks to improve outcomes by reducing the delay between occurrence and treatment, and is seen as taking a more holistic approach, including consideration of vocational outcomes. Outcomes such as relapse are also reduced.
- Employment for people with mental illness is an outcome in the NHS Outcomes Framework, but this is not supported by specific outcomes in the Clinical Commissioning Group Indicator Set.
- Back to Work support is provided by the government through Personal budgets and the Care Programme Approach. Access to Work and the new Health and Work Assessment and Advisory Service are valuable in terms of supporting people to remain in work. Settled and secure housing is vital to any back to work strategy.
- Out of work benefits include Jobseekers Allowance or Employment Support Allowance. People requiring them may be referred to a range of programmes, including: The Work Programme, Work Choice or, 'Get Britain Working' schemes.
- Vocational rehabilitation is primarily provided through Supported Employment services. The Individual Placement and Support or IPS model has been widely evaluated in the US and Europe and is seen as the best model for getting people with schizophrenia into open competitive employment.
- Effectiveness of the IPS model is seen as requiring fidelity to the eight principles of IPS, as well as the integration of an Employment Support Specialist into the CHMT or EIT.

The weight of evaluative and practitioner evidence in support of many of these interventions is considerable, yet employment rates for people living with schizophrenia remain very low. Our conclusion is that, in large part, this is a problem of coordination, vision and implementation. In the final chapter we summarise our main conclusions about the nature of this problem and suggest a series of recommendations which, we hope, will raise aspirations and deliver better outcomes.

5 Conclusions and Recommendations

Despite considerable progress towards inclusiveness in the last forty years, dark corners remain in parts of the 21st century labour market. Systemic disadvantage and poor outcomes for some groups, such as ex-offenders, people with learning difficulties and those living with serious mental illness are part of a long list of issues where little progress has been made, and our expectations of making real headway remain depressingly low. This report has focused on labour market outcomes for people living with schizophrenia – a severe and enduring mental illness which can have a significant impact on functional capacity at a number of levels – clinically, socially and economically. Employment rates for people living with schizophrenia are among the lowest for any group of working age adults in most developed economies yet, as our research has found, there is both a powerful evidence base and strong consensus about the nature of the barriers to employment which they face and, more importantly, how to overcome them.

In this final chapter we address three fundamental questions:

1. Given the compelling and mostly unarguable evidence base for a range of well-known and road-tested interventions to support people with schizophrenia into sustainable, competitive employment, why have we made no appreciable dent in unemployment rates?
2. If we can agree that the status quo is unacceptable but not inevitable, whose job is it to do something about it, what should they do and what should they do first?
3. Even if we manage to improve employment rates for people living with schizophrenia, how can these improvements be sustained and how can we ensure that we are maximising access to good quality jobs for those able to aspire to them?

Despite the considerable barriers to employment faced by many people with a diagnosis of schizophrenia, we have collected sufficient data through speaking to people who live with schizophrenia and to their family and friends, and to those who work in the front line of clinical interventions, those who provide employment support, as well as informal care, to convince us that there are grounds for optimism. Persistence, coordination, imagination and realism will all be needed, but the pathways to employment, recovery and inclusion are clear.

5.1 Evidence and Action

The findings set out in this chapter illustrate that the array of interventions available to support people living with schizophrenia to play a more active part in the labour market is strongly supported by evaluative evidence. In the right circumstances, and delivered effectively, psychosocial interventions, pharmacological interventions, Individual Placement and Support (IPS) vocational interventions and other community mental health interventions can all be relied upon to deliver improved clinical and employment outcomes in many cases. So why is implementation of, and access to, these interventions so patchy and piecemeal? A few reasons became apparent during our research:

- **Individual differences.** Schizophrenia affects every individual differently. Illness-related factors, such as the onset and type of symptoms, the timing of the diagnosis, and co-morbidities, and social factors such as capability for self-management and available support networks, all vary by each case. Because no one with schizophrenia is the same, it is challenging to develop an employment support service strategy that would work for all.
- **Attitudes and expectations.** Many people with schizophrenia are very motivated to work, but expectations about employment among stakeholders vary greatly. Even though the majority of experts we interviewed were generally positive about work, many people have low expectations about how well someone with schizophrenia would be able to adapt to long-term, competitive employment, and often it is not seen as an achievable outcome. Stigma by others, often leads to self-stigma, impacting on their initial motivation.
- **Timeliness of interventions.** Because employment rates among people with schizophrenia are so low, efforts tend to focus on getting those who are unemployed into work, rather than supporting those already in education or employment to remain. With more timely interventions it should be possible for those young people with schizophrenia still in education to manage the transition to the world of work and for those people who receive a diagnosis while in a job to stand a better chance of retaining it.

It is striking that, in the case of Individual Placement and Support (IPS), there is both a strong evidence base and a broad consensus that employment outcomes are improved if its principles are adhered to consistently and with high 'fidelity'. So why is IPS not being rolled-out consistently and with energy across the UK? The answer is complex, but it seems to be attributable to a combination of factors, including inconsistent knowledge of IPS among healthcare professionals, lack of funding, inability of some healthcare

and employment support services to work together and employment as an outcome for people not being seen as a priority for recovery. This is not a domain where more evidence is needed before we commit to implement an intervention. What we need is political will to prioritise work as an outcome for more people living with schizophrenia, and the resources to make it happen.

5.2 Calls to action

The solutions to the problem of low employment rates for people with schizophrenia lie in the hands of many stakeholders. We have identified a few things that various groups with an interest in improving the situation can do. Where these involve government, and particularly health, social care and employment policy-makers, these efforts need to be coordinated and 'joined-up', initially by a Minister.

So, who should do what? Here is our list of recommendations.

Government

While there have been solid improvements in the priority given to mental health in UK health policy in recent years, and much greater awareness of the prevalence and impact of mental illness as a public health and workforce issue, more can be done to support people with schizophrenia to remain or become active in the labour market. We believe that the Government should:

- **Reaffirm employment as an outcome.** Updating the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) (formerly known as the 'Commissioning Outcomes Framework' or 'COF') to include employment as an outcome is essential as it enables Primary Care to support job retention and the return to work of people with chronic conditions from the earliest stages. That would also allow more rigorous data collection on the employment status of people with severe mental health conditions. The data would make it possible to critically evaluate the effectiveness of current interventions aiming to improve return to work and job retention.
- **Implementation of the Health and Work Assessment and Advisory Service.** Implementation of the service, as set out in the government's response to the Sickness Absence Review, is important to ensure that people in danger of slipping out of the labour market as a result of serious mental illness receive both clinical and vocational support in a timely manner.

- **Expand the focus of the government’s response to the Independent Review of Sickness Absence to include severe mental health.** Whilst we welcome the focus on common mental health conditions (such as anxiety and depression) and employment in the government’s response to the Review, particularly the promise to include ‘more support for GP education on mental health and employment’, we feel that this should be expanded to include severe mental health conditions (where appropriate).
- **Review of the Work Capability Assessment (WCA).** It is necessary to make adaptations to the WCA to make it more sensitive to the functional capacity fluctuations experienced by people with schizophrenia and other severe mental health conditions.
- **Development of a national plan to increase employment rates of people with severe mental health conditions.** It is essential that the Government establishes a task force of multi-disciplinary experts, chaired by Ministers from both the Department of Health and the Department of Work and Pensions to design a plan for the UK to increase employment rates among people with schizophrenia to 25 per cent within a decade.

Improvements in labour market outcomes for people living with severe mental illness cannot be achieved by one Government department working in a ‘silo’. Multi-agency working is needed if we are to make a breakthrough where previous efforts have failed.

Healthcare professionals

We recognise that for GPs, psychiatrists, clinical psychologists and other healthcare professionals, implementing appropriate treatment regimes and stabilising symptoms are most often the dominant priorities when managing the care of someone with a diagnosis of schizophrenia. However, we have found that, for many individuals, remaining in – or returning to – work is an aspiration which could more frequently be reflected in care plans. We believe healthcare professionals should:

- **Ask patients about their work history and their employment aspirations at the earliest opportunity.** For many people with schizophrenia work is important and may be a realistic outcome. It may also have therapeutic benefits. Employment should be taken into consideration when making decisions about treatment.

- **Seek early advice from employment support specialists.** They can advise on pathways back to employment and reinforce clinical interventions. An approach based on the notion that symptoms must be stable before employment can be considered may not always be the case.
- **Focus on capacity, not incapacity.** Schizophrenia is undoubtedly a serious illness, but it is important to emphasise what someone living with the condition can do rather than what they can't due to their functional impairments. If we are to encourage self-management, increase social inclusion and facilitate a return to paid employment, a positive attitude is important both with people with schizophrenia and with their families and carers.
- **Informing GPs and Community Mental Health Teams.** They need to have more information on the relationship between severe mental illness and employment. The evidence base for supported employment and other interventions should be made more accessible to those in the 'front line' of care to avoid the persistence of negative views about employment influencing the care and advice given to those living with schizophrenia. Multi-disciplinary education and training for healthcare professionals should be available to avoid 'siloed' thinking.
- **Continue to invest in Early Intervention in Psychosis Services.** The service plays a significant part in helping to prevent relapse. This, in turn, enables people living with schizophrenia to re-engage successfully with activities of daily living, their education and even with employment.
- **Provide peer support service.** Peer Support Workers should be part of every Community Mental Health Team and Early Intervention Team. The evidence shows they are valued by service users and can support self-management and return to work, as well as providing opportunities for empowerment of people with mental health conditions, though using their experience to help others.

We do not underestimate the complexity of managing the clinical care of people living with schizophrenia and we recognise that many are sometimes too ill to work. But we also know that – for better or worse - many people's expectations about their medium to long-term chances of working are set by advice given to them by clinicians. We hope that the evidence presented in this report makes a compelling argument for work as a realistic outcome for more people who are living with schizophrenia.

Employers

Overall we found that – in employment terms – people suffer more from a diagnosis of schizophrenia than from the symptoms of the illness itself. By this we mean that the stigma attached to serious mental illness is so powerful that avenues to social inclusion, recovery and employment are often closed shut, even for people who are well or have their symptoms reliably under control. We know that almost a third of UK employees say they would never work with someone with a mental illness (The NHS Information Centre for health and social care, 2011) and that many employers feel drastically ill-equipped to employ people with a diagnosis of schizophrenia. Nonetheless, we believe that employers should:

- **Seek information on severe mental health conditions and how they can be managed in work.** Ensure that you are sufficiently well-informed and prepared to respond if an employee discloses that they have a serious mental illness such as schizophrenia. This may be by having access to occupational health expertise or by seeking professional support from a patient advocacy organisation (such as Rethink Mental Illness or MIND), from a local NHS provider, from a private health insurer, or from a supported employment provider.
- **Develop an open, friendly work environment to enhance disclosure.** Many people with schizophrenia decide not to disclose their condition to their employer or their co-workers because of the ignorance and stigma surrounding schizophrenia in wider society. If your organisation's culture makes disclosure unlikely or impossible it is less likely that an employee with schizophrenia will be able to access the support they need. This will lead to a greater impact on your business.
- **Be prepared to make adjustments at work to accommodate the needs of people with schizophrenia.** In many cases these adjustments will relate to working time and providing flexibility. Often they can be constructed in conjunction with the employee, who will – perhaps with input from an employment support specialist or clinician – be able to indicate which working patterns or job responsibilities need to be adapted to allow them to remain productive at work.

Although stigma surrounding mental health in workplaces is reducing, it still represents a major barrier to employment for people with serious mental illness. Most employers could do more to help – mainly through providing a supportive environment and working with staff with mental illness to take simple steps to redesign work around their needs.

Families and carers

We have spoken to family members and carers of people living with schizophrenia. They can live through periods of extreme frustration and despondency when faced with a system which can feel fragmented, glacially slow and where stigma and ignorance lies around every corner. Yet family members and carers can be the most effective agents for coordinated and integrated support for their loved ones. Our research concludes that they should:

- **Get access to support.** It can be easy to feel that you are alone against the system but this should never be the case. There are many organisations that can help you to navigate your way through the services that offer support to people with schizophrenia and their families. Some of these can be accessed through GPs and other healthcare professionals and others through patient advocacy organisations, charities and employment support organisations.
- **Support their aspirations and goals.** It is important that you and the person you care for have shared goals around how you can support them in their aspirations. It may be about finishing off a course of study, getting or keeping a job, living independently or pursuing a creative interest. Whatever it is, it will be easier to achieve if you work together.

Family and carers can make a crucial difference to outcomes for people with serious mental illnesses like schizophrenia. These outcomes are more likely to be positive if you can be a positive and energetic coordinator of information, advice and practical support. You have the right to be demanding of the services on offer and to ensure they are tailored to the specific needs of your loved one.

People with schizophrenia

A diagnosis of a serious mental illness like schizophrenia might be a shock for some and a relief for others. Though at times, the idea of being in a job may seem remote and unimportant, at others it will be realistic and desirable - a chance to feel well and be part of a meaningful and fulfilling activity which provides an income. Our research shows that employment in an open competitive market is a realistic option for many more people living with schizophrenia. We suggest that you should:

- **Help yourself to keep well.** Getting to know yourself and the events or feelings which might cause you stress and trigger your illness is an important aspect of self-awareness and self-management. Everyone is different, but keeping well by identifying what keeps you on an even keel and doing more of it can help you

succeed in getting and keeping work. Part of this process is to focus on your talents and strengths rather than on your illness and how it might sometimes limit you.

- **Make sure that your employment aspirations are heard by your healthcare team.** Even if the priority right now is to establish the most appropriate treatment for you and to help you to manage your own health, there is likely to be a point at which work becomes something you aspire to, and your healthcare team can support you in this. They can help you to access the support available to help you and your family. You should certainly seek advice from an employment support specialist who will be able to help you think through your options.
- **Try to choose appropriate work.** If you know that certain things, such as dealing with customers, stresses you out, then you need to consider this when making choices about types of work. If there is a job or career you strongly desire, but you are concerned that it might cause you stress at times, then make sure you have got supports in place to help you pursue it and to deal with any setbacks along the way. If you can't find a job that reflects your interests and talents, remember that you can also address this in things you do outside work – you may be able to get support to try out work that interests you, or you can take up a related hobby. This also can be a stepping stone to your goals – don't lose sight of them.
- **Stay positive.** The job market is tough at the moment, but our research has uncovered many great examples of people with schizophrenia in long-term, meaningful employment. Do not let your condition control your life – there are many options and support available to help you to manage your illness and move your life forward.

5.3 Sustaining Success and Aiming Higher

We are in a labour market where, for many people with chronic or fluctuating health conditions, keeping or getting a job is regarded as an achievement in itself. But by 2030 at least 50 per cent of the working age population of the UK will have at least one long-term health problem. This means that it is not enough to say that 'any job is a good job'. Ultimately, it is important to people's health and wellbeing that they have access to fulfilling jobs, and that we avoid employment 'ghettos' which are reserved for the socially excluded or the chronically ill.

While, in the case of serious mental illness, we are starting from a low base we feel strongly that we should aim higher than policies and practices which focus on just getting people off benefits. We need an inclusive labour market populated with inclusive workplaces, supported by a healthcare and welfare system which prioritises good quality work as a clinical outcome.

We recognise that there is some distance to travel before we reach this stage but what constitutes success with people with severe mental illness should be a benchmark we should be brave enough to set ourselves.

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Appendix 1 Expert Interviews

We interviewed a range of experts with experience in the field of schizophrenia. The following is a brief summary of the kind of people we interviewed and their job roles.

Employment support workers

Several of the participants we interviewed were assisted in their job search by an Employment Worker. The employment workers we questioned came from a small charity which focused on helping those with mental disabilities into employment. Much of their work concentrates on helping those with mental disabilities focus on what it is they want to do, providing assistance with job searches, and supporting them throughout this process. It is quite common for Employment Workers to liaise with and work in unison with other support workers also helping the participant, such as healthcare professionals, their Care Coordinator or their Disability Employment Advisor via JobCentre Plus. Importantly, employment workers also work with employers, helping them not only in the interview stage, but also within the job itself.

Employers

We talked to people from companies of several different sizes, from different sectors, and included those who had hired people with schizophrenia and those who had not.

Healthcare practitioners and academics

Importantly we interviewed a number of people who work within the current medical system, who work with and support those with schizophrenia daily.

Nurse consultants are nurses who specialise in a particular field of care. Half of their time is spent working directly with patients. The rest of their time is spent developing personal practice and research and evaluation.⁵¹

Occupational therapists (OT) work with mental health patients, helping them to build up their confidence. Their work focuses much more on the day-to-day life of their patients, helping them gain the social and practical skills to help them within social, domestic and leisure settings. Although historically focused on in-patient care, in recent years there has been a move towards occupational therapists working with out-patients as well. This work varies, and can include them working directly with employers and even training them about the special requirement of those they are trying to help. OTs may be employed by a health authority, a social services department or a voluntary organisation.

51 NHS Careers website 'Nurse Consultant' (Accessed 22/10/12, <http://www.nhs.uk/explore-by-career/nursing/careers-in-nursing/nurse-consultants/>)

In a similar field to occupational therapists, but more specialized, are vocational managers. The vocational manager we spoke with worked in an organisation devoted to helping people with mental health issues into work, and supporting them whilst in employment. These roles generally use the IPS system.

We also spoke with psychiatrists and psychologists. Generally psychiatrists tend to focus on the clinical and medical side of treatment, whilst psychologists provide counselling, and can help the assessment of mental health conditions, depending on whether they are focused on counselling or clinical psychology.⁵² Psychological therapists (or psychotherapists) aim to help their patients with long term counselling and therapy, and tend to go deeper than other forms of counselling.⁵³

As part of our work we also spoke to those from the more academic sphere, including academic psychiatrists and economists. Whilst not having quite the same lived experience as many of the others we interviewed, their knowledge on the subject proved invaluable.

Carers and Family

Many, such as the family members, friends and carers we talked to, provide a more informal form of support to those they look after. They provided an invaluable insight into the personal lives of the interview participants.

52 MIND 'Who's who in mental health: A brief guide' (Accessed 22/10/12, http://www.mind.org.uk/help/research_and_policy/whos_who_in_mental_health_a_brief_guide#psychiatrist)

53 Ibid

Appendix 2 Biographies of Participants with Lived Experience

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After suffering depression during her first year in college and being persuaded to leave, the participant had a schizophrenic episode as a result of the shock and the sense of failure. She was later diagnosed with schizophrenia. After a brief period in hospital, which she found helpful, she has since been treated primarily at home. She has received support from a variety of different healthcare staff, including a psychiatrist who *'would talk to me about how I was doing, what ways I found – maybe getting into something like activities, like exercise, diet. And then eventually got into training, work, things like that. She prepared me for it until I was ready for it'*. During her journey back into employment she was also supported by an employment worker, a cognitive therapist and a community psychiatric nurse.

Since her initial diagnosis she has had a variety of short term roles. After a period working in the administration sector, for which she underwent training and received a useful and relevant qualification, she moved into the care and health sector. Unfortunately she suffered a relapse and was unable to continue.

She is currently unemployed, and has some concerns over her experiences of working in the past, saying that *'Even though you want to work, it just sometimes the experience of mental health, it just gives you that limitation on what you can handle at work and what you can do and cannot do.'* The participant is volunteering with her Church, assisting with both the Sunday School and general administration. At the time of interview she was applying for a volunteer placement in the health sector. Whilst recognising the difficulties of returning to employment, she is hopeful - *'I know that I'll work again because I have worked before so I really find that's a positive way of going, to find out more about the condition and stuff'*.

File: 100

Diagnosed later in life than the other participants, the participant has had a highly varied employment history. After leaving school at the age of 16 he undertook some vocational training, but did not complete his studies. Since then he has worked in a variety of different sectors, ranging from sales, to manufacturing, to retail and customer services. He sees work as being important, being about *'whether I can pay the bills, and it keeps you from getting up to mischief on the streets and that. And you're able to go places and socialise.'* He has had several spells of unemployment, including a period at the time of his diagnosis. He believes that his illness was the cause of his unemployment at this time.

Although the participant has been in paid work since his initial diagnosis he has been unemployed for the last two years, and is currently looking for part-time work. At the time of our conversations with him he was looking forward to a job interview in the sales industry in the following week. This interview had been brokered with the help of an employment worker, who he described as *'very supportive'*. When asked where he sees himself in five years time he said that *'I would like to have some regular work you know... Suitable work, suitable work like I could handle.'*

File: 101

In his late 40's at the time of the interview, the participant was diagnosed with schizophrenia shortly after completing a higher level degree, when he was aged between 22 and 24 years old.

Since then he has been in and out of employment, with several long term-jobs, a work placement and some periods of long-term unemployment. This most recent spell in unemployment led to him receiving support from two third-sector organisations, which helped him to find his current position. He describes *'They've given me guidance, they've given support and they've provided the facilities as well to help me look for employment and also even they assured me that I can do, they've given me that 'can do' attitude, which I apply.'*

Although he has been unable to progress into a job suiting his initial degree, working in primarily entry level and often manual roles in the hospitality, leisure and service industries, he is hopeful that he might have the chance to pursue a career more in line with his education in the future.

Throughout this time he has not disclosed his mental health problems to his employers, although they are aware that he was referred to his current position from a third-sector organisation that specialises in helping those with mental health problems. When asked if disclosing his condition to his employer would be beneficial he responded by saying *'I think it would make no [positive] difference at all. I don't want them to find [out], with the attitude they have.'*

File: 102

A young women in her early 20s, the participant was diagnosed when she was 18 years old, during her A-Levels. After a brief period of illness she went on to complete a higher level degree. She has a varied work experience background, with a considerable amount of ad hoc work relevant to her career. Whilst she may not enjoy all the work, especially where it's not in the sector she wants to work in, even then she says that *'when I'm working ... I do feel better.'*

She now regularly volunteers for a large charity, is in part-time paid employment in an entry level, service-focused sector, and regularly takes on small temporary jobs that are in line with her long-term career plans in the creative sector. Her employment worker has been impressed by her efforts to find employment in this industry, saying that *'she's produced articles for journals and all sorts of things. She continues to do artwork and enter competitions. So ... she does a lot.'* Since being diagnosed she has been supported by a psychologist, her university's disability support service, a third sector organisation, and a Community Psychiatric Nurse, whom she found particularly helpful. Her CPN helped her *'to articulate myself properly and talk about myself. And get to know myself and then after that, I started to be more confident talking to friends.'*

File: 103

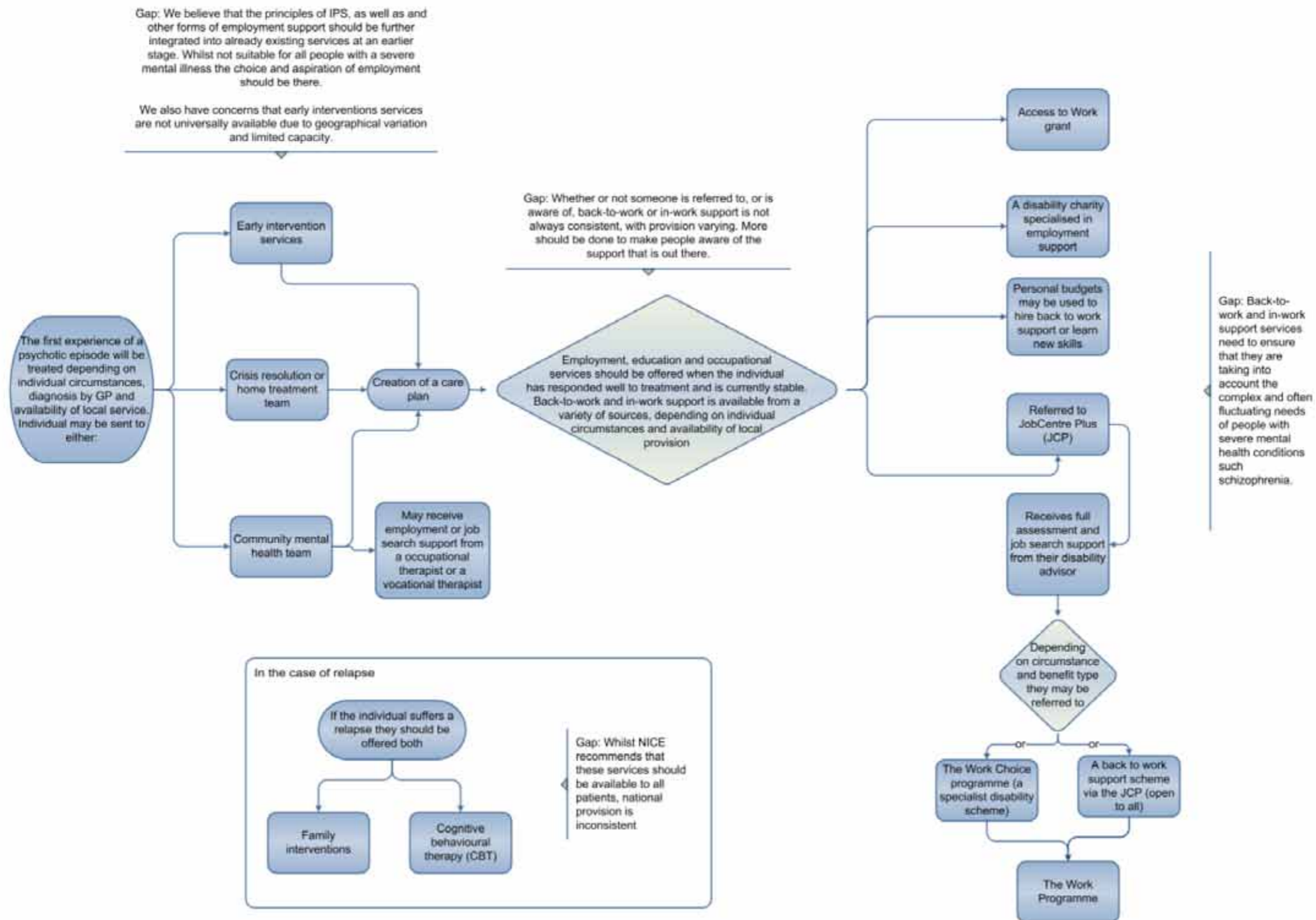
The participant was diagnosed when she was 14 years old and still in school. As a result of this she was unable to complete her GCSES at the time. Despite suffering several relapses, the participant has also enjoyed long stable periods, and is currently in college. She has had some work experience in the customer service industry and has undertaken a voluntary placement at a charity.

Currently looking for part time work to fit around her studies, she is being assisted in her search by a third-sector organisation who she says *'helped me building up my CV, my covering letter, and also helping me to just know that I can do it when I get out there... [they have been] preparing me when I go to interviews and see how to do, and how to be.'*

This organisation is also helping her find a voluntary placement over the summer holidays, which may help her further her career plans. She hopes to go to university in the future. When asked to describe what work meant to her she said, *'Work? For me it's waking up in the morning. Work for me is doing something that you enjoy, because when you enjoy something, no matter how tired you are, you will get up and do it. But if you don't enjoy it, there's no point.'*

Appendix 3 Employment support and interventions available for those with a severe mental illness: where are the gaps?

An ideal journey- it should be noted that this diagram is based on government and NICE guidelines, and does not take variation of provision into account



Abbreviations

CBT	Cognitive Behavioural Therapy
CCGIS	Clinical Commissioning Group Indicator Set
CHMT	Community Mental Health Team
CPA	Care Programme Approach
DH	Department of Health
DWP	Department for Work and Pensions
EIP	Early Intervention in Psychosis
EIT	Early Intervention Team
ESA	Employment Support Allowance
ESS	Employment Support Specialist
IAPT	Improving Access to Psychological Therapies
IB	Incapacity Benefits
IPS	Individual Placement and Support
JSA	Job Seekers Allowance
NAS	National Audit of Schizophrenia
NICE	National Institute for Health and Clinical Excellence
OT	Occupational Therapist
SE	Supported Employment
UC	Universal Credit
WCA	Work Capability Assessment
WHO	World Health Organisation
WRAG	Work Related Activity Group

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