

# Working with schizophrenia: Experts' views on barriers and pathways to employment and job retention

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## Abstract.

**BACKGROUND:** Unemployment among people with schizophrenia remains high despite slight improvements in vocational rehabilitation services and attitudes towards people with mental health disorders over the years. Experts are in a good position to increase our understanding on why this group still experiences such significant barriers to employment.

**OBJECTIVE:** Interviews explored experts' views on schizophrenia and employment; with a particular focus on individual, attitudinal and structural barriers, as well as available interventions and their outcomes.

**METHODS:** The sample of 20 experts were recruited using theoretical sampling. The experts consisted of: employment specialists, healthcare professionals, activists from patient organisations, academics, caregivers and employers. A thematic approach was used for analysis.

**RESULTS:** Low expectations of healthcare professionals which were often manifested as minimal recognition of employment as an outcome for people with schizophrenia as well as a "benefits trap" were identified as the strongest barriers to employment. In addition, the IPS model was identified as the most effective to support people to work, but lack of funding to implement the model nationally and concerns of poor implementation were raised by the experts.

**CONCLUSIONS:** More research is required to examine which adaptations are needed for vocational interventions in order to implement them successfully.

Keywords: Schizophrenia, employment, outcome, vocational intervention, attitudes, healthcare professionals

## 1. Introduction

People with schizophrenia encounter one of the highest unemployment rates among all vocationally disadvantaged groups (Kilian & Becker, 2007; Marwaha &

Johnson, 2004). A large international study combining data from 37 different countries found that on average, 19 percent of people diagnosed with schizophrenia were in paid employment, with figures ranging from 16.2% to 22.6%, against an average employment rate in the general population of 75%–80% (Haro et al., 2011). In the UK, the Schizophrenia Commission reported a much lower employment rate, with an average of 8% and a range of 5%–15% (2012).

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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, & Kendall, 2008) including, for example, better cognitive functioning (Christensen, 2007; Giugiaro et al., 2012). In addition, it has been found that those in competitive employment were less likely to experience relapse (Schennach et al., 2012), and were more likely to achieve clinical remission compared to those who were unemployed and/or those in sheltered employment (Haro et al., 2011).

The importance of work for recovery of people with mental health conditions has been increasingly recognised among healthcare professionals and other stakeholders (Cook & Razzano, 2000; Tsang, Leung, Chung, Bell, & Wai-Ming, 2010). The NHS Outcomes Framework 2013/14 recognises improved functional ability through employment in mental health illness as a specific outcome (The Department of Health, 2012). In addition, vocational rehabilitation has become a legitimate focus for community mental health centres serving individuals with severe mental health illnesses in some countries, especially the USA (Bond, Drake, & Becker, 2012; Rosenheck et al., 2006; Rosenthal, Dalton, & Gervey, 2007).

Available evidence, however, suggests that people with schizophrenia may not have benefitted from improved attitudes and services as much as those with other psychiatric disorders. It has been suggested that vocational rehabilitation interventions do not work as well for people with schizophrenia as they do with for people with other severe mental health conditions (Cook & Razzano, 2000). While employment rates for people with other severe mental health conditions have slightly increased or stayed stable over the years the same trend has not been seen in schizophrenia. Indeed, rates among people with other severe mental health conditions are notably higher, for example, a recent systematic review of nearly five thousand people with established bipolar disorder found that approximately 40%–60% were in competitive employment (Marwaha, Durrani, & Singh, 2013) which is considerably higher than for those with schizophrenia. Evidence indicates that the very low employment rates seen for people with schizophrenia are not intrinsic to having the condition, but 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 (Gioia, 2005; Marwaha & Johnson, 2004).

There is good evidence that healthcare professionals and employment specialists, as well as family members attitudes toward an individual's employability, have an influence on individuals ability to gain and remain in employment (Giron, 2004; Marwaha, Balachandra, & Johnson, 2009; O'Connell & Stein, 2011; Schulze & Angermeyer, 2003). The attitudes of health care professionals have also been found to play an important role in terms of the information clinicians gather on their patients' employment, the needs they identify as important to their patients and what interventions they offer or consider relevant (Marwaha et al., 2009).

In addition, the experts are in good position to contribute to our understanding on why unemployment rates remain low and how to improve the situation. The experts can also give insights into why exiting vocational interventions achieve the effects that they do in real life settings. The qualitative methodology allows us to go beyond individual's experiences and opinions to explanations for how and why some of the aspects of the interventions work (or do not work) and further give further insights into current policies and their implications for people with schizophrenia.

## 2. Research questions

We conducted expert interviews as a part of the applied research project at The Work Foundation titled: "Working with Schizophrenia: Pathways to Employment, Recovery & Inclusion" (Bevan, 2013). The expert interviews were conducted to explore schizophrenia and employment, with a particular focus on the individual, attitudinal and structural barriers, as well as to receive their views on interventions that help people to stay at work or enter into working life. Keeping these broad objectives in mind, we developed the following research questions:

- What are the barriers to finding and remaining in employment for people living with schizophrenia?
- What are the most important factors that influence the ability of people with schizophrenia find and remain in employment?
- 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?

Table 1  
Study participants

Job role	Number of participants interviewed	Quoted
Academic psychiatrist	2	AP I, AP II
Clinical psychiatrist	1	CPI
Caregiver	3	C I, C II, C III
Expert with lived experience (campaigner, activist)	2	ELE I, II
Employer	3	E I, E II, E III
Employment support specialists (employment support worker/vocational service manager)	3	ESS I, ESS II, ESS III
Nurse consultant	1	NC I
Stakeholder (mental health organisation)	1	S I
Psychologist	2	P I, P II
Occupational therapist	2	OT I, OT II
Total	20	

The research was used to inform policy recommendations on how to increase the number of people with schizophrenia who are active in the labour market. We directed our messages to different stakeholders, including the UK government, but also to people with schizophrenia, healthcare professionals, and employers and caregivers to advise how they can better support people with schizophrenia to work and at work, as well as considering what people with schizophrenia may be able to do for themselves.

### 3. Methods

#### 3.1. Data collection

To allow flexibility in the recruitment process, we used theoretical sampling to recruit subject matter experts into the study. The experts were recruited via mental health organisations, hospitals, universities and word of mouth using existing links with various stakeholders. The sample consisted of a wide range of experts who were either providing vocational or occupational support for people with schizophrenia (e.g. employment consultants, occupational therapists); or were responsible for their medical care (e.g. psychiatrist). We also interviewed people who had considerable knowledge and experience of the topic area due to personal experience or research. This included activists from patients groups, academics and caregivers. We also interviewed a number of employers to ascertain the barriers from their side.

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 experts' views on the labour market benefits of early diagnosis and intervention practices in order to identify innovative policy and practice.

The interviews were conducted between May 2012 and November 2012. The study participants were interviewed either by a telephone or face-to-face and all of them gave either verbal consent (telephone interviews) or written consent (face-to-face interviews). All the interviews were audio-recorded and transcribed verbatim. Each interview lasted from 30 to 60 minutes. Table 1 describes the participants and provides a key for this paper's quotations.

#### 3.2. Analysis

Thematic analyses were used to identify commonality and difference in the participants' experience. The method is particularly suitable for analysing semi-structured interviews that aim to identify themes and patterns of experiences and behaviour (Lindlof & Taylor, 2002). We developed a list of themes using previous literature on schizophrenia and employment. We were guided by the general approach of the grounded theory method allowing new material emerging from the data (Strauss & Corbin, 1997). The Theoretical sampling method allowed flexibility during the research process; making it possible for researchers to alter the recruitment plan during the data gathering so that the data reflected what was actually occurring in the field rather than speculations of what cannot or should have been observed (Glaser, 1992). Flexibility in the recruitment process meant that different questions could be asked of a sample depending on experts' subject knowledge and perspective (Coyne, 1997).

The themes were supplemented or modified whenever new information emerged. Categories and logical relationships were used to classify and interpret the data. The data were corroborated by multiple readings of the transcripts and considered adequate when the nature of the findings seemed to be iterated. The first

author (TT) coded all the interviews. All the transcripts were checked by the second author (KS) or the fourth author (RT) after the interpretations of the first author. Disagreements were discussed and resolved mutually. An Excel processor (Microsoft Word 2011, USA) and NVIVO were used to facilitate data processing and management.

## 4. Results

The main aims of this study were to identify barriers of access to work and job retention in people with schizophrenia and also to investigate available vocational interventions particularly focusing on what makes those services successful. Finally, we identified the limitations that those vocational interventions have.

### 4.1. Barriers to employment

#### 4.1.1. Low expectations

Low expectations of people with schizophrenia within society in general, as well as a cautious and sometimes negative attitudes from health care and other professionals towards an individual's ability to enter open competitive employment, were identified as considerable barriers to employment among this group. Interviewees perceived that there was often doubt, as to how well someone with schizophrenia would be able to adapt to long-term, competitive employment.

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

*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. NC I*

*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 do this, that or the other to work. They need to do pre-potential training to work - all the myth., 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. ESS I*

The considerable stigma faced by people with severe mental health conditions, particularly schizophrenia, was named as one of the strongest barriers to accessing employment. According to some experts, people with schizophrenia can suffer more from the diagnosis than the actual illness.

*I think there's a lot of stigma and damage associated with receiving a diagnosis of schizophrenia. P II*

*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. P I*

The stigma and low expectations of others, often leads to self-stigma, impacting on the initial motivation to work or seek employment. What came through clearly in interviews was the perception of low self-esteem and low confidence among people with schizophrenia with regards to their capability 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. P II*

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

*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. E I*

Our interviewees showed concern about the impact of work on wellbeing, highlighting that they were apprehensive about the potential for relapse if 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. C I*

*If people with psychosis have difficulties in coping with stress. And that can exacerbate psychotic symptoms. P II*

On the other hand, some experts, especially those working in vocational support, expressed the view of work being too stressful as a myth, and emphasised the therapeutic importance of work.

*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. ESS II*

*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. ESS III*

#### 4.1.2. Work as an outcome

One of the main barriers identified by the majority of the experts was the low recognition of employment as an outcome in terms of decisions about treatment and management of the condition. Though seen as possibly having improved in recent years, there remained a clear concern among interviewees about the lack of priority, or in some cases the lack of any consideration, given to employment in health and social care services for people with schizophrenia.

*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. NC I*

*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. ESS III*

It was argued by some healthcare professionals we interviewed, however, that work should not be seen as a priority for people with schizophrenia because the primary outcome of treatment 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, as work was less of a clinical outcome, and more of a social outcome for the majority of people with schizophrenia.

*What health professionals need to do is try to improve the patient's 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. AP I*

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

Experts widely supported the view, however, that people diagnosed with schizophrenia, as a group, should not be overlooked for a role because of their condition. This support was to varying degrees, which might be seen to reflect the extent to which the respondent was involved with vocational rehabilitation. Perhaps unsurprisingly, positive views were strongest among those with a larger role in this area.

*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. P I*

*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. OT I*

The type of job considered appropriate for an individual with schizophrenia was contingent upon that of individual's characteristics. It was emphasised during the interviews that different people have different skills, interests and qualifications as with the broader popula-

tion, and that the presence of schizophrenia should not deflect from that.

*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. E III*

*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. AP I*

*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. ELE II*

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

#### 4.1.3. Welfare benefits

Whilst the welfare system is a vital intervention in supporting many people with schizophrenia; it appeared to be a barrier to employment in some cases. It came across during the interviews 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 widely known as the benefits (or welfare) trap.

*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. C III*

Interviewees frequently mentioned the impact the benefits system had on people they knew – with several giving examples of undertaking appeals in relation to loss of benefits, including employers who on occasion had to get involved to assist people currently in work. The stress of worrying about benefits was also seen as having an impact on individual's ability to work and self-esteem.

*If she is on benefits, maybe the lowest the lowest, because she was telling me, "Mum, I have to go*

*to court because I have to fight them taking my benefits". C I*

*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. E I*

*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. E II*

The assessment process and eligibility requirements for receiving benefits were viewed negatively by all those who raised it in our interviews. The negative impact on individuals with schizophrenia going through the assessment process was a clear concern, and for some the requirements are seen as unrealistic and as putting people under unnecessary stress.

*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. C II*

*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. E II*

## 4.2. Interventions and their implications on employment

### 4.2.1. Pharmaceutical and psychosocial interventions

In our interviews, pharmaceutical interventions were seen as important in terms of supporting people to manage their symptoms of their condition. Anti-psychotic medication was particularly identified as important in terms of controlling positive symptoms (including delusions and hallucinations) and preventing relapse. In particular, some experts considering them as crucial in allowing someone with schizophrenia to be able to engage in living normal life including employment.

*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. P II*

*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". OT I*

*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'. P I*

Though the value of antipsychotics was broadly agreed upon by experts we interviewed, the message came across clearly that decisions on appropriate pharmaceutical interventions should be based on the assessed needs and specific situation of the individual seeking treatment, with some conceding that medication might not always be effective, or in some cases appropriate.

*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 unman-*

*ageable ones, and it's variable as to who that group is. CP I*

*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. P I*

*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. NC I*

Compliance with medication may reduce the likelihood of an individual experiencing an episode of psychosis – an experience likely to be detrimental to the individual's health, wellbeing and recovery, as well as to employment outcomes and particularly job retention. This was a clear message in the interviews – one employer explained how they included compliance with medication in a workplace agreement they had devised with the employee to assist their retention.

*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. E II*

Side-effects of medication were stated as one of the most common reasons for withdrawing; in some cases the side-effects were so severe that the experts considered them to have a serious impact on their patients' ability to work. It was suggested that it was sometimes unclear as to whether it was the symptoms of the illness causing behaviours which impacted on ability to work, or if it was in fact side-effects of the treatment.

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

*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. C II*

*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 to differentiate which is causing what. P I*

Such concerns led some experts to emphasise the need to look at a broader approach to treatment and management of schizophrenia than just pharmacological interventions, particularly with regards to recovery, and achieving indicators of recovery such as employment.

*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. ELE II*

Psychological therapy and psychosocial interventions are often used alongside pharmacological interventions for the treatment and management of schizophrenia. Not unsurprisingly, experts interviewed in this study were positive about such interventions, highlighting their value in terms of social functioning, problem solving, understanding and coping with symptoms, and self-esteem; all of which are factors associated with having a positive effect on employment outcomes.

*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. S I*

#### 4.2.2. Back to work support and vocational interventions

Many experts mentioned Early Intervention for Psychosis services (EIP) in terms of supporting young people (16–35 years) in their recovery and life goals. The service was seen as taking a more holistic approach than traditional mental health services, with education and occupation included as one of the ten 'core features' of EIP. This was viewed very positively by the experts we interviewed, who called for an expansion of this approach into other mental health services.

*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. P I*

*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. NC I*

*I think people who are working in early intervention and psychosis services . . . . are probably geared up to think more about supporting people back into employment or education. OT II*

*I think that's the difference between EIP 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. P II*

In regards to direct vocational rehabilitation, supported employment and 'Pre-vocational Training' were both raised by several experts. The interviews reflected the evidence and the growing consensus in the UK that 'Pre-vocational Training', or place then train models are costly and ineffective.

*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. C III*

*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. AP II*

On current evidence, Supported Employment models, and particularly Individual Placement and Support (IPS), is the most effective method for helping people with severe mental health conditions who want to work, to achieve sustainable competitive employment.

*When they do wish to return to work, there is a large a body of evidence around IPS – it helps them get to work. AP II*

Experts identified various factors that they saw as driving the success of IPS. This included the emphasis placed on finding a role based on an individual's existing skills and experience, along with finding an employer who is happy to take them on, and building a relationship with them. In addition, several study participants mentioned 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 [Improving Access to Psychological Therapies] and CBT [Cognitive behavioural therapy] but IPS is better; it promotes social inclusion, and it needs better promotion nationally. OT I*

The fact that IPS offers assistance to employers as well as employees, providing them time-unlimited support, was also seen as particularly valuable in terms of increasing employer's confidence in taking employees on initially, as well as supporting retention and sustained employment.

*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. ESS III*

This ongoing support is provided by Employment Consultants – whose role was also highlighted as a critical element to a successful IPS service. Having a

designated person who has responsibility for getting clients into employment was seen as very valuable.

*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. C I*

In terms of retention, the on-going support element was seen as providing a buffer for employees in the event that they experience a downturn in their condition, and returned to a treatment program which did not emphasise employment. As an expert explained to us, without the on-going support and involvement of the Employment Consultant, many people with schizophrenia have found themselves with little option but to leave their jobs to focus on their health and well-being:

*It 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. ESS II*

Co-location of Employment Consultants in the mental health care team was also seen as beneficial in that context. In our interviews, experts were positive about Employment Consultants being increasingly included in the community mental health teams (CMHT).

*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. ESS III*

Co-location of services and inclusion of Employment Consultants in mental health care teams was also seen as valuable in terms of encouraging health care professionals to give more focus to employment as an outcome.

*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.* ESS I

It was emphasised however that although employment and health services can be co-located, 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.* NC I

Other features of the Employment Consultant role were less clear cut in terms of experts' expectations of the role. For example, it was argued that the job search and job retention functions should be separated.

*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.* ESS II

In our interviews, a wide range of suggested and anticipated roles were identified for Employment Consultants in terms of providing support for clients. There was an expectation that support would be 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...* NC I

*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.* ESS I

#### 4.2.3. Problems in vocational interventions

Though experts were uniformly positive about vocational interventions, and particularly Supported employment IPS, they highlighted a number of concerns which presented barriers to potentially successful interventions. One of these related to the healthcare system itself. It became evident from the interviews, that in some cases mental health services were not well-coordinated or 'joined up' with one another, or with 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 mental health 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.* C I

The concern was also raised in interviews that despite the positive outcomes for those undergoing EIP, the costs involved has led to a reduction in services, rather than an expansion to incorporate the positive elements into standard or mainstream care (i.e. CMHTs). There was a clear concern among some experts that some NHS Trusts dilute the model, which naturally reduces its impact.

*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.* P II

*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 its 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.* P I

*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. ESS II*

The lack of coordination and varying philosophies between more vocationally-centred services (such as EIP) and more 'traditional' service provision was raised in interviews as being damaging to employment prospects, in that the momentum that was built up by the services that take a more positive view of employment, was being destroyed again quite quickly.

*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... P I*

Concerns were raised in the interviews about the difficulty of integrating IPS into normal practice. Several experts mentioned the fact that IPS is not currently widely implemented into routine clinical practice 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. ESS III*

Just like in EIP services, it became clear in our interviews that current investment in IPS 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. P II*

As a result of funding cuts, the increased case loads of Employment Consultants were often mentioned; the experts were concerned about the effect it may have for the quality of the service.

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

Even though IPS services are intended to provide ongoing support for both employers and employees, the limited resources and variable availability nationally of IPS services mean that this is not always an option, and services may not be able to achieve what they intend. Some experts discussed how services did not meet their expectations in the longer-term. Such resourcing issues also mean that IPS services often do not have the capacity to offer support to people with schizophrenia who have not been employed through the service. Employers highlighted the lack of access to support for current employees as a concern for them.

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

*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. E II*

The need for wider access to IPS, was discussed by several participants of our study, many of whom called for national implementation. It was argued that this need not be an expensive development, but could be managed through ensuring that currently available funds are better targeted on services that matter most to the service users, and are most effective.

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

*It's not about spending more money on services – it's making the most of them. OT II*

## 5. Discussion

Our results reflect the previous findings showing that the low expectations of society for people with schizophrenia are strong barriers to employment. There is a body of evidence indicating that people with schizophrenia are affected by stigma in multiple areas of their lives, especially in employment (Marwaha & Johnson, 2004; Schulze & Angermeyer, 2003; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). A European study looking at experiences of discrimination and recovery found over 40 per cent of participants reported moderate or high levels of self-stigma, and almost 70 per cent reported moderate or high perceived discrimination (Brohan, Elgie, Sartorius, & Thornicroft, 2010).

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 et al., 2009). People with schizophrenia have also reported lack of encouragement to work from mental health professionals (Marwaha & Johnson, 2005). It has been argued that mental healthcare professionals are no less susceptible to stigmatizing beliefs than the general population (Ping Tsao, Tummala, & Roberts, 2008; Schulze & Angermeyer, 2003). Thus, the low expectations of healthcare professionals on their patients' capability are perhaps presented in low recognition of employment as an outcome for people with schizophrenia; this was clearly identified as a barrier to employment among people with schizophrenia in our interviews.

Motivation to work has been found important to vocational outcomes in people with schizophrenia (Davis, Nees, Hunter, & Lysaker, 2004; Poon, Siu, & Ming, 2010; Tsang et al., 2010). Self-stigma caused by the low expectations of others may have a considerable effect on an individual's motivation to work (Catty et al., 2008; Corrigan, Larson, & Rusch, 2009). In one study on case managers' expectations of employment outcomes for people with schizophrenia, for example, it was found that the clients with case managers of higher expectations were more likely to remain employed longer than those whose case managers had low expectations (O'Connell & Stein, 2011). As a result of low expectations, 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) this may be particularly true in work life. A cross-sectional study of people with schizophrenia across 27 countries found that 64 per cent anticipated discrimination when applying for work, training or education (Brohan et al., 2010). More tellingly, over a third of participants anticipated discrimination in job seeking when none had been experienced (Thornicroft et al., 2009). Low motivation and self-stigma may also cause people to avoid accessing and using healthcare 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 et al., 2009).

Healthcare professionals are also likely to raise concerns in relation to type of work; 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 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; Scheid, 2005). This view, however, was not the most prevalent among the experts we interviewed. It was a common belief that the type of job that is appropriate for an individual with schizophrenia is reflecting them as individuals with characteristics beyond a diagnosis of schizophrenia. It was highlighted that, like the broader population, different people have different skills, interests and qualifications. The level of positivity varied depending on the each expert's role, but in general, the attitudes towards the employability of people with schizophrenia were positive. It has been noted in previous studies that the effects of medical treatment and availability of vocational interventions for those diagnosed with schizophrenia contribute to different patterns of vocational recovery; meaning abilities to perform job-related tasks will vary greatly by each individual (Major et al., 2010; Marwaha et al., 2007; Rosenheck et al., 2006).

There is some evidence from previous studies that healthcare professionals have increasingly started recognising employment as important for recovery for people with schizophrenia (Tsang et al., 2010). Therefore our findings may also support the notion of improving attitudes among healthcare professionals and other experts. On the other hand, however, studies looking at stigmatising attitudes toward people with mental health problems among healthcare professionals have found that they are more likely to hold positive attitudes toward people with mental health problems who are recovering from their illness or whose

illness is in remission (Linden & Kavanagh, 2012; Rao et al., 2009). People with schizophrenia who seek vocational rehabilitation or who are working are naturally not “fundamentally ill” and therefore our finding may just reflect better attitudes toward employed people with schizophrenia or those seeking for employment rather than generally improved attitudes.

It has been argued in several studies that many people who potentially could work may not attempt to do so for fear of losing their benefits and not having sufficient income (Marwaha & Johnson, 2005; Rosenheck et al., 2006; Tsang et al., 2010; Turton, 2001). In addition, only a few IPS clients, for example, work full-time, likely due to limited stamina, but also because of fear losing their benefits (Bond et al., 2012). There was evidence of the “benefits trap” in our study; several experts mentioning the negative impact of the benefits system on people with schizophrenia with many giving examples of individuals going through the assessment process of receiving benefits or undertaking appeals in relation to loss of benefits. These processes were seen as causing unnecessary stress and possibly having an impact on their work functioning. There is a paucity of research, however, on the effects that benefits system processes have on individuals’ work ability and work functioning; this question clearly warrants further study.

There is evidence that people with schizophrenia are unable to manage the process of appeal after initial benefits denials (Harvey et al., 2012). In the UK, the conditionality of disability related out-of-work benefits such as Employment and Support Allowance (ESA) have been made tighter, with the introduction of the Work Capability Assessment (WCA), which is designed to assess whether a person “fit for work” and an increase in the level of sanctions for those claiming ESA if they do not attend the work focused interviews or the work related activity. It should be noted, however, 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 (Griggs & Evans, 2010) found little evidence to suggest a long-term positive effect of sanctions. The review also suggests that sanctions generally lead to unfavourable effects on longer term outcomes such as earnings over time, child welfare and job quality. Thus, 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 effective.

The need for wider access to IPS, was discussed by several participants of our study, many of whom called for national implementation. We found evidence in our research of problems with implementing the IPS model which is, without a question, the most effective vocational rehabilitation approach for people with severe mental health disorders. Even though IPS services are intended to provide on-going support for both employers and employees; according to our interviews, this was not always the case and some experts (employers, in particular) discussed on how services did not meet their expectations in the longer-term. This could be due to the limited availability of IPS services, but it could also reflect poor implementation of the existing service. Diminished effectiveness of the model has been attributed to labour and disability policies. Interestingly, evidence from qualitative studies suggests that the problems with implementation of the IPS are formidable and represent a challenge that is not found in the USA (Bond et al., 2012). A recent large study testing the feasibility of implementing evidence-based supported employment care for people with severe mental health disorders showed that implementing complex interventions are feasible in routine mental healthcare (Drake et al., 2013). Further international studies, however, are needed to examine the nature and strength of the policy factors to determine what adaptations to the model are needed in order to successfully implement it nationally in the UK.

## 6. Conclusions

Our study supports previous findings on barriers to employment for people with schizophrenia. Low expectations of healthcare professionals expressed as low recognition of employment as an outcome for people with schizophrenia; the benefits trap; limited access to vocational rehabilitation and problems with implementing the model at a national level represent the biggest barriers to employment for people with schizophrenia. Our results indicate that better co-ordinated support and increased recognition of the importance of work for recovery among healthcare professionals, considerably larger numbers of people with schizophrenia could both gain access, and remain within, the labour market. Increasing the employment rates of people with schizophrenia is, however, a complex issue, requiring critical evaluation of existing services to determine required adaptations in order to develop effective services for people with schizophrenia and support them in their vocational goals.

## 7. Study limitations

To maximise the validity and reliability of our findings, we conducted our interviews according to carefully designed protocol, and we rigorously applied theoretical sampling in recruitment and we were guided by the grounded theory method and previous literature to identify themes from the interviews. We instructed analysis in order to identify themes independently of each other and discrepancies were then discussed and resolved mutually. However, because our sample size was small (20 informants) and recruited from relatively easily accessible organisations in England, we can only offer modest inferences of generalisation of our findings and recommendations to stakeholder populations across different countries in a wider variety of settings. In addition, because of each participant was interviewed only once and because of our sample consisted only 1–3 participants in each job subcategory; we likely missed opportunities to learn more about each expert group perspective.

## 8. Recommendations

Given the complexity of the issues, they need to be approached from a number of angles in order to make relevant recommendations to different stakeholders.

Steps must be taken to increase recognition of the importance of employment as a treatment and recovery outcome for people with schizophrenia who desire it, among health care professionals and to commissioning bodies, such as the Clinical Commissioning Groups, to the end of supporting employment aspirations, and ensuring that treatment decisions do not negatively impact on work aspirations. This requires a two-pronged approach. Firstly awareness about the relationship between mental health and employment needs to be raised through training and education for all HCPs with a role in the treatment and management of people with schizophrenia. Secondly, healthcare professionals should be motivated in this regard by making employment an outcome on which patients are assessed. In the UK, this could mean including employment as a clinical outcome at the Clinical Commissioning Group Outcomes Indicator Set, or being driven through the Commissioning for Quality and Innovation (CQUIN) payment framework, or inclusion as a NICE Quality standard.

Access to evidence-based interventions which have demonstrated improved employment outcomes should

be implemented more widely and made accessible to those who would benefit from their existence. In particular there is now a significant body of evidence demonstrating that IPS Supported Employment improves employment outcomes for people with schizophrenia. Similarly, EIP services have had positive results in terms of educational and employment outcomes, as well as on recovery. In order to successfully implement the services, critical evaluation needs to put in place to ensure successful implementation nationally.

Governments must ensure that the welfare system does not act as a disincentive to finding employment. As well as this, the needs of people with severe mental health conditions such as schizophrenia need to be specifically considered in designing policy and services in this area – ensuring they are given the same consideration as physical health conditions.

In the UK, the issue of employment for people with health conditions cuts across government departments and sectors – where responsibility is not assigned to specific parties, there is a risk that these issues may fall through the gap between health, social and employment services. There needs to be a cross-departmental national plan to increase employment rates of people with severe mental health conditions, coordinating interventions across departments and funders.

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