

# Schizophrenia and employment

Putting the lived-experience of schizophrenia  
at the heart of the employment agenda



Briefing supported by Janssen





## Foreword

At SANE we are acutely aware of how difficult it is for people to break through the many closed doors they meet to reach anyone who might consider them able to work.

Only 8% of people with schizophrenia are in work, and this number is far too low when we know that many more would like to and may be able to be in employment.

Putting the lived-experience of schizophrenia at the heart of the employment agenda is informed by a survey of people with schizophrenia that we carried out to understand some of the reasons why employment rates might be so low and what can be done to improve opportunities.

Behind the statistics lie a range of unique personal stories. Employment, or other activities such as volunteering, training and education may be an important part of maintaining wellbeing and recovery for many people with schizophrenia.

The Government has rightly prioritised the issue of employment and mental illness, and there are now important national goals designed to ensure that health and social care services seize the agenda. But we will not deliver on these national ambitions and provide realistic opportunities to individuals, such as those who answered our survey, unless we can encourage and promote those at local level.

Our report outlines a range of key recommendations for parliamentarians and policy-makers. We need local health services that are given incentives to commission the psychological therapies and employment support services that we know work. Alongside this, we need to ensure that health services, local authorities, employment services and local employers drive progress in their area.

There is still such a lack of knowledge and fear surrounding a diagnosis of schizophrenia. Yet it is only through being given the chance to work and be valued for their contribution that people already deprived by this illness can have their hopes and confidence restored.

Marjorie Wallace CBE  
Chief Executive, SANE

## Schizophrenia and employment

- At a national level, there have been a number of important policy developments and key NHS policy levers introduced to promote the prioritisation of employment for individuals with schizophrenia.
- In order to explore how such policies may impact in practice, SANE surveyed people with schizophrenia about their experience of employment.
- The condition, which affects men and women equally, is most likely to be diagnosed between the ages of 15 and 35. This can prove especially debilitating for people at important stages of both their personal and professional lives.
- Employment rates for people with schizophrenia are low. It is estimated that only 8% of people with schizophrenia in the UK are employed<sup>1</sup>, compared to a national employment rate of 71%.<sup>2</sup> This is despite the fact that many people with schizophrenia state obtaining work as a significant factor in their recovery journey. For example, of participants in our survey who were **not** engaged in employment or related activities, **59.4%** said they would like to be.
- In this parliamentary briefing, we outline some of the key findings of our survey which aim to ensure that the individual service user experiences inform practice with regard to employment for those with a diagnosis of schizophrenia. It sets out key recommendations for action, including what parliamentarians can do locally to seek to ensure that health services and employers in their constituency work together to improve employment opportunities for people with schizophrenia.

## Recommendations

- A realistic and informed incentive around employment and mental illness needs to be developed in the Clinical Commissioning Group Outcomes Indicator Set (CCGOIS)
- Clinical Commissioning Groups should ensure that they prioritise access to evidence-based psychological treatments and 'train and place' employment support services, such as Individual Placement and Support (IPS).

## What parliamentarians can do

- 1 Highlight the need for an indicator on employment and severe mental illness in the Clinical Commissioning Group Outcomes Indicator Set by asking questions in Parliament and writing to the Minister for Mental Health.**
- 2 Find out about levels of local access to the psychological therapies and Individual Placement and Support.**
- 3 Promote awareness-raising for local Clinical Commissioning Groups about the benefits of employment for those with mental health conditions, including schizophrenia.**
- 4 Promote local conversations between constituents with schizophrenia, mental health professionals, and employers about improving local employment opportunities.**

## What is schizophrenia?

Schizophrenia is a mental health condition, falling into the category of what is known as a psychotic illness. It is commonly misunderstood, partly because the words schizophrenia and psychosis are inaccurately used in a variety of contexts.

Psychosis simply means that a person has sensory experiences, thoughts or beliefs that are not shared by the majority of people. These may include delusions, hallucinations and disordered thoughts.

## What might a diagnosis of schizophrenia mean?

Approximately 1 in 100 people will experience the illness at some point in their lifetimes.<sup>3</sup> It can be a severe illness and it may be distressing and frightening for both the individual and those around them. However, symptoms can be treated and many people respond well to treatment.

Around one third of those diagnosed with schizophrenia experience **one episode only**, another third may have occasional episodes, while one third may have to live with it as a long-term condition.<sup>4</sup>

## National policy

Supporting the employment of people with long-term conditions, including mental illness such as schizophrenia, has been outlined as a key initiative across the Government's plans for health and social care. It appears as a key indicator in the NHS Outcomes Framework, the Public Health Outcomes Framework as well as the Adult Social Care Outcomes Framework.

This commitment has been given further emphasis through its inclusion within the Mental Health Implementation Strategy<sup>5</sup> and as an indicator within the NHS England Mandate<sup>6</sup>.

### The key levers

- NHS Outcomes Framework<sup>7</sup>
- Public Health Outcomes Framework<sup>8</sup>
- Adult Social Care Outcomes Framework<sup>9</sup>

## About our survey

SANE's survey provides a snapshot of the experiences of people with schizophrenia in regards to employment. 79 people answered questions about the key barriers they face in finding and staying in employment and what support might be helpful.\*

While national policy relates to employment objectives our survey was cognisant of other activities such as volunteering, education and training. For some, such activities may act as steps towards employment; for others, they may be ends in themselves, for instance if their condition is not stable enough to enable employment to be a realistic objective at a particular time.

Behind the statistics lie a range of unique personal stories. Employment, or other activities such as volunteering, training and education may be an important part of maintaining wellbeing and recovery for many people with schizophrenia. However, what this means and how this can be achieved for each individual with a lived-experience of schizophrenia may vary.

\* This briefing and survey have been produced by SANE, with financial support from Janssen. Janssen provided input to the development, scope and design of the survey and report. SANE retain editorial independence and editorial control of the findings of the research and has exclusive ownership of all intellectual property arising from it.

## Experiences of employment, volunteering, education and training

- 57.5% of the people who responded were engaged in some sort of work, volunteering, training or education. However, over one-third (41.6%) were not engaged in any such activity.
- Of those who were not in some sort of work, volunteering, training or education 59.4% wanted to be.

## Past engagement versus current engagement

The table below gives figures on the past and present engagement of those surveyed in work or related activity. There was a distinct difference between the number of people who had been engaged in employment or training in the past and the number of people who were currently in employment. Whilst there could be a range of reasons for this, it is worth considering whether or to what extent, the barriers outlined in this document have had an impact on the respondent's current situation.

The recent Work Foundation report '*Working with schizophrenia: Pathways to Employment, Recovery & Inclusion*' states that 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 contrast to a UK-wide working age employment rate of 71 per cent.

Type of activity	Past engagement <i>Have you been in any of the following in the past?</i>	Present engagement <i>Which of the following are you in?</i>
Full-time paid work	75.7%	35.6%
Part-time paid work	50%	20%
Volunteering	56.8%	33%
Higher education	55.4%	22.2%
Training	33.8%	8.9%

## Key themes from our survey

### 1. Healthcare needs and support

There are range of barriers to employment for someone with schizophrenia that are associated with the condition itself, including fluctuating symptoms, problems of relapse, and the negative symptoms such as low energy, morale and depression.<sup>10</sup>

Making employment a realistic goal for someone with schizophrenia involves addressing their specific healthcare needs and providing ongoing healthcare support, which is also mindful of the needs and demands of their employment role.

Demonstrating that this is possible, a significant percentage (**70.1%**) of people who took part in the survey reported that their condition was stable due to an effective treatment and support regime. Stability of this kind may make employment a more achievable goal. Moreover, moving towards work, whether through training, volunteering or paid employment, can itself be helpful in achieving stability.

#### Survey respondent:

*“ Relapses are possible and knowledge of my condition allows the host organisation to make other arrangements to cover my leave. ”*

It is therefore important to understand how the health service can support access to effective treatment and support. In our survey 70% of people stated that problems in finding appropriate treatment and support were barriers to finding or staying in work.

Access to the most appropriate care and treatment will be a vital component in helping someone to find and stay in work.

#### Survey respondent:

*“ Please DON'T say to patients 'You'll never get better' or 'It (schizophrenia) won't go away' and please review medication regimes regularly. ”*

To what extent do you agree that each of the following issues are a barrier to finding or staying in work?				
	Fluctuating Conditions	Problems in finding appropriate treatment and support options	Problems adhering to medication	Managing contact with mental health services
Strongly agree	57.1%	32.9%	18.8%	25.7%
Agree	28.6%	37.1%	20.3%	35.7%
Neither agree nor disagree	8.6%	20%	23.2%	27.1%
Disagree	2.9%	8.6%	30.4%	7.1%
Strongly disagree	2.9%	1.4%	7.2%	4.3%

Many respondents were also open about the difficult symptoms and side-effects that they have to deal with and how these impact on their opportunities for finding and staying in work. Respondents acknowledged that such factors may present challenges for potential employers as well.

#### Survey respondent:

*“ I feel that it is vital to inform a potential employer regarding the nature and manifestations of suffering from schizophrenia. It is important to convey the boundaries and limitations which are features of the disorder. Unfortunately, the nature of this illness is the reality of not being reliable or consistent. ”*

**85.7% said that fluctuating symptoms were a barrier to finding and staying in work**

The following quote demonstrate some of the key barriers:

#### Survey respondent:

*“ As already stated, the inability to control the more disturbing aspects of suffering from schizophrenia is a real barrier to finding and staying in work. Also, stigma can be incredibly destructive, resulting in periods of intense paranoia. The fear of financial instability is another important factor, as my condition means that I cannot be reliable in the workplace, or in training or further education. As the very nature of psychosis fluctuates wildly, so does my capability to be consistent. ”*

### Accessible co-ordinated care

More accessible and better coordinated services is clearly an important aspect in supporting employment. Fragmented care pathways between primary care and community care can result in poorer outcomes for patients, while also encouraging higher referral rates. Therefore, it is vital to ensure seamless care-pathways to help someone with schizophrenia to have the support available to them at the most appropriate times.

Over one in three participants in our survey said that better co-ordination between health professionals would be very helpful in the context of seeking and keeping employment. Almost six out of ten respondents, 59% said that this would help them. Furthermore, 63.6% also said that managing their contact with mental health services was a barrier to their employment.

#### Survey respondent:

*“ The problem is that mental health provision very often has no 'joined up handwriting' approach and will often keep to their own specialty. Where possible, all individuals should be provided with cross-agency support, or allocated a team of specialists to work with in co-ordinating a cohesive strategy based on need, not on cost. ”*

## Relationships with health professionals

An important factor in helping people with schizophrenia to recover and move towards employment is a positive, encouraging relationship with health professionals. We asked whether people had felt encouraged by health professionals to find or stay in work.

Have you felt encouraged by a health professional to find or stay in work?	
YES	NO
48.6%	51.4%

Over half of people who answered did not feel encouraged by health professionals, which emphasises the work that is needed in this area. Whilst each situation will be different, every health professional should feel able to encourage people with schizophrenia to consider how they might move towards a situation where they can be involved in employment or related activities.

At the centre of this is the relationship between the service user and the healthcare professional. Below are some of the issues that people faced:

### Survey respondent:

*“ It seems to me that permanent unemployment is seen by many in the caring professions as the natural state for people with a diagnosis of schizophrenia and I would strongly challenge that view. ”*

### Survey respondent:

*“ Mental health services seem orientated to people out of work and on benefits (who at least seem to assume this). They should equally help and support people who are in work or who want to work. They should acknowledge people’s life goals. (I wanted to work, and would have liked to have got married). ”*

## 2. Perceptions of schizophrenia: stigma and discrimination in society and the workplace

A diagnosis of schizophrenia can carry significant stigma within society. From the comments we received, stigma associated with schizophrenia acts as a barrier to work or related activity for three main reasons:

1. A lack of awareness about the capability of people with schizophrenia to work.

### Survey respondent:

*“ I wouldn’t want to be judged on my mental health instead of my skills. ”*

2. A reluctance of employers to employ people through fear or prejudice of people with schizophrenia.

### Survey respondent:

*“ I have mentioned my condition in the past and was told I was unstable for the work place and unreliable. ”*

3. Employers actively discriminating against people.

### Survey respondent:

*“ People just don’t understand. I have had a job but was sacked once they found out. ”*

## Fear of stigma

Our survey attempted to explore the impact of the fear of stigma versus actual experience of stigma or discrimination in the workplace. The findings demonstrated that the level of fear of stigma was higher than actual levels of experienced stigma or discrimination.

*Fear of discrimination (85.7%) and fear of stigma (87.1%) in the workplace were two of the highest rated barriers in terms of finding and keeping work. This compared with 65.2% who reported having actually had previous experience of discrimination in the workplace*

### Disability law

The Equality Act (2010)<sup>11</sup> contains provisions to prevent people from being discriminated against because of disability. If a person’s mental health condition has a serious impact on their day-to-day life over a long period then this could be classed as a disability. In addition, employers have a duty under the Act to make ‘reasonable adjustments’ for people with mental health conditions to enable them to remove or reduce or prevent the obstacles a disabled worker or job applicant faces.

## 3. Building confidence and skills: support and training programmes

With the right support many of the barriers addressed in this briefing can be tackled, making employment a realistic goal for people with schizophrenia.

Our survey returned some very informative findings on this matter. When asked what kind of support they would find most helpful in terms of finding and keeping work, the top three highest rated were:

- Ongoing support whilst in work 75.8%
- Mentoring & support with specific understanding of schizophrenia: 72.7%
- Specific support re self-management of condition 63.6%

Our survey revealed that **65.6%** of respondents were not aware of support options available from the Department of Work and Pensions. While the survey did not enable an examination of this statistic, the figure nonetheless seems to indicate not just a lack of awareness on the part of individuals, but also on the part of health professionals who may have been providing encouragement about employment, without being fully aware of the practical support available. However, 53.8% of respondents had been involved in the Pathways to Work initiative\*, and 23.3% in the Access to Work scheme.\*\*

**Survey respondent:**

*“ I think any schemes to get mental health service users back to work must be tailored to their specific needs and understand the fluctuating nature of mental illness and the side effects medication can have.”*

## Training

People with schizophrenia are most likely to be diagnosed between the ages of 15 and 35.<sup>12</sup> This therefore can have a significant impact on individuals' professional development, including training. Our survey indicated that 37.9% of participants felt that specific training in job-related skills would be very helpful.

**Survey respondent:**

*“ A more comprehensive understanding of the impact of living with schizophrenia by those involved in employment or training and education is vital. Ongoing support from relevant agencies and a desire to comprehend how extreme the disorder can become must be put in place.”*

## Financial support

Financial pressures were listed by **77.2%** of survey respondents as a barrier to seeking and keeping work. Perhaps not surprisingly, advice about benefits was identified by 42.4% of respondents as very helpful in terms of finding and seeking employment. Participants recounted the difficulties of navigating a benefits system which did not always have an understanding of, or an ability to accommodate, the fluctuating nature of their condition.

## Priorities moving forwards

### Support in Primary Care

From April 2013, Clinical Commissioning Groups (CCGs) will be charged with commissioning mental health services. This means that primary care will take on a significant responsibility for promoting employment opportunities for people with schizophrenia.

A survey of 1,500 GPs has revealed that almost two-thirds (64%), were unaware of evidence suggesting that work is beneficial for physical and mental health.<sup>13</sup> Most said that if they knew of this evidence, it would affect the advice they give. There is a need to both increase awareness in primary care and develop incentives or levers to promote action.

\* Pathways to Work is a Department of Work and Pensions programme designed to help people receiving Employment and Support Allowance or incapacity benefits find work. Support is tailored specifically for each person taking part in the programme, and is delivered alongside Jobcentre Plus and a range of other organisations.

\*\* The Access to Work programme is a Jobcentre Plus grant scheme assisting disabled people who are in paid employment by providing practical support in overcoming work related obstacles as a result of their condition. Grants are also provided to employers to contribute towards additional employment costs resulting from disability.

The Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) (formerly known as the 'Commissioning Outcomes Framework' or 'COF') is the lever through which NHS England will drive improvements and hold CCGs to account. At the moment there are no incentives in the CCHOIS for CCGs to address employment.<sup>14</sup>

The following quote from the survey shows the opportunities for primary care to support employment opportunities:

**Survey respondent:**

*“ I was helped by one particular GP, who knew my psych diagnosis, but focused instead on the fact that I was a university graduate, and encouraged me to think of receiving Invalidation/ incapacity benefit as temporary.”*

## Psychological therapies

Psychological therapies, such as Cognitive Behavioural Therapy (CBT), are recommended by the National Institute for Health and Care Excellence (NICE), and evidence shows that they can help people who are able to work to enter the workplace. Moreover, psychological support whilst in work is important in helping people to address specific issues that might make it difficult to hold down work and remain in the workplace, such as energy and motivation.

Since being introduced in 2007, the Government's Improving Access to Psychological Therapies (IAPT) programme has successfully improved access to psychological therapies for people with mental health problems. However, people with severe mental illness were not covered by this programme until February 2011, when 'Talking Therapies: a four year plan of action'<sup>15</sup> was published alongside 'No health without mental health, a cross-government strategy'.<sup>16</sup>

In 2012 the Government announced that as part of its IAPT Programme, it would provide funding to all Primary Care Trusts to make available one employment advisor for every eight therapists by 2013. Despite this, the funding arrangements are for 'local determination,' meaning that in practice IAPT therapists may choose not to have an employment advisor.<sup>15</sup>

## Individual Placement and Support (IPS)

Individual Placement and Support (IPS) is the most well-established and evidence suggests it is the most effective 'place then train' method. One study of IPS has showed that it was twice as likely to achieve employment as other vocational and rehabilitative services (55% versus 28%).<sup>17</sup>

Through IPS an employment specialist works with an individual to advise on employment opportunities and provide support when in work. IPS is usually integrated in to the work of Community Mental Health Teams (CMHTs) which has been shown to be effective, with specific best practice examples in London. However, despite the benefits of IPS, the availability of support nationally is variable meaning that people who could benefit from such help are missing out.

**Survey respondent:**

*“ I have an employment officer who has been great in helping me find employment but also keeping me in employment, in the past once I have found employment the employment officer has stopped contact as this time.”*

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