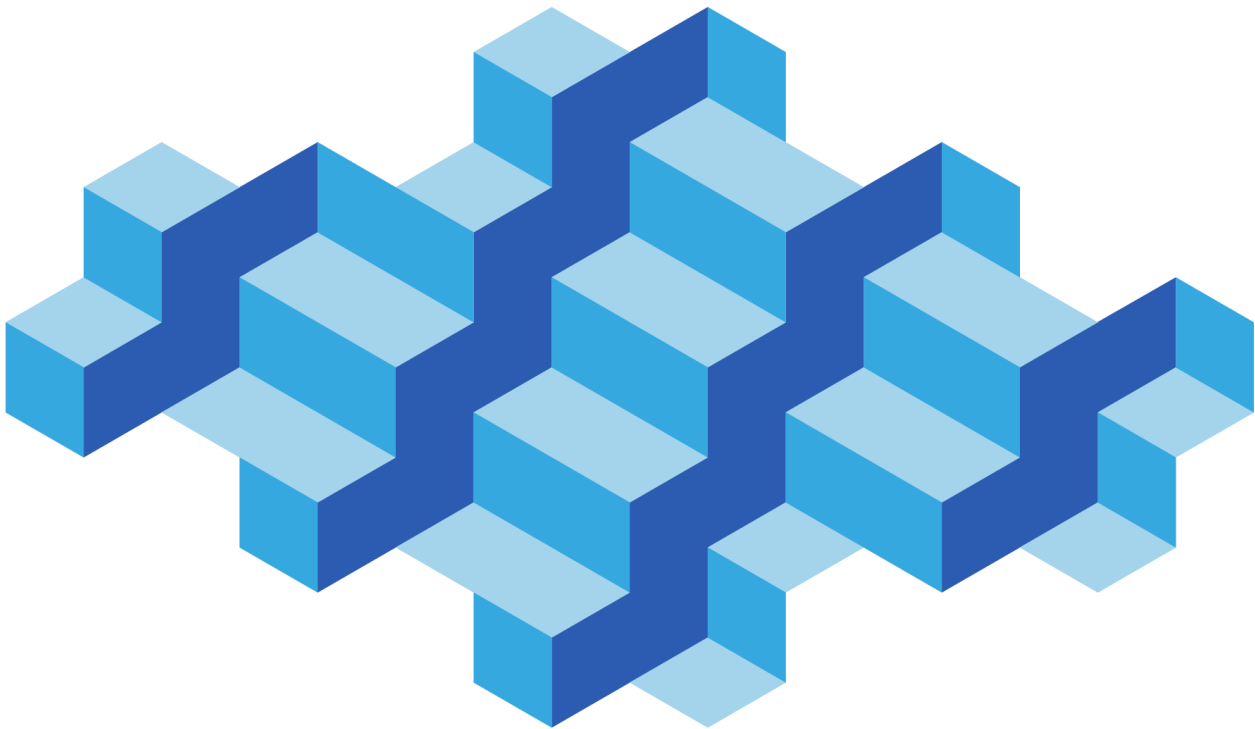


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## **Working with Schizophrenia:** Employment, recovery and inclusion in Germany

Karen Steadman



The Work Foundation transforms people's experience of work and the labour market through high quality applied research that empowers individuals and influences public policies and organisational practices. For further details, please visit [www.theworkfoundation.com](http://www.theworkfoundation.com).

## Preface

There has been ample discussion of German labour market reforms, e.g. in OECD Economics Department Working Papers, and these reforms are thought to have contributed to the strength of the German labour market response to the international financial crisis of 2008-2009 (Hüfner & Klein, 2012). But still, people experiencing severe mental illness in Germany face serious difficulties in achieving integration in the competitive labour market.

This “Working with Schizophrenia” report presented by The Work Foundation is a brilliant piece of work, and the exercise upon which the report builds should be praised for thoroughness. The report is comprehensive, and it has looked into all component parts of the German vocational rehabilitation and supported employment systems. Descriptions of institutions such as *Berufstrainingszentren* (BTZ) and *Rehabilitationseinrichtungen für psychisch Kranke* (RPK) are precise and ecologically valid, they tell us what these services can achieve and what their limitations are within the framework of mental healthcare and employment support systems. Also, the report describes the legislative framework relevant to the field of vocational rehabilitation, and it does so with a thorough understanding of social legislation in Germany.

The report is right in focusing on key issues such as barriers to employment in general, and stigma and discrimination in the labour market and workplace in particular, and this is rightly set in the context of international evidence that people with severe mental illness face discrimination when they seek employment (Corrigan, Powell, & Rüscher, 2012). The report addresses *barriers* to employment among people with severe mental illness including individual health, psychopathological symptoms, relapse and the issue of motivation. The report is right in advocating that supported employment approaches should be taken on board more by BTZ and RPK services. In its call-to-action section, “Working with Schizophrenia” is right in highlighting the imperative to conduct high-quality research in the field.

With very little empirical research published, for example on RPK services in Germany, much more research on service availability and on social, clinical and quality of life outcomes is mandatory. A paper as simple as the before-and-after study on RPK users presented by Stengler et al. (2014) highlights some strength in an inert job integration system by reporting a proportion of 38 per cent being employed and 26 per cent in education and retraining at the end of the RPK intervention, i.e. 64 per cent of patients being in employment either in the general labour market or in educational measures at RPK discharge.

The report is right in highlighting the issues of collaboration and integration of health and vocational services, and it rightly points out that alternatives to sheltered workshops must be strengthened. The authors have been thorough in their effort at exploring and understanding the German system of services, they describe the system of sheltered workshops (WfbM)

with due respect but they also insist that people with psychosis seeking jobs must be able to move between different service types and components of the system. Finally, their call to action that “work” must be considered a key outcome in care systems for people with schizophrenia pinpoints a key challenge for any modern inclusive service for people with severe and enduring mental illness.

Above all, The Work Foundation report is a brilliant piece of work in putting together verbatim quotes from a very comprehensive series of interviews with people who have lived experience of caring for someone with a severe mental health problem, with those with personal lived experience of psychosis, and with experts such as psychiatrists, occupational therapists and employment specialists working in the field. Ten interviews with persons with personal lived experience are a highlight of this report, and the thorough understanding of the German reality of work for people with severe mental illness is illustrated, e.g., by the section on between-Länder differences that have a strong impact in a mental health rehabilitation system strongly shaped by federalism.

This is an impressive piece of work that is likely to be of interest to both readers abroad and to those readers familiar with but struggling to understand the complicated mental health care and job integration systems in Germany.

***Thomas Becker and Steffi Riedel-Heller***  
***Ulm and Leipzig, February 2015***

## Executive summary

This report highlights the barriers experienced by people with schizophrenia in Germany to entering and remaining in the open labour market, and considers what can be done to overcome them. The evidence demonstrates that employment is an achievable and sought after goal for many people with schizophrenia. For many, a return to work is associated with recovery. In this sense alleviation of symptoms is rarely seen as an end in itself, but more a means to the end of living a full and meaningful life which often includes employment. Indeed, work can be invaluable for those who want it, providing a sense of purpose, dignity and social inclusion. **The Work Foundation argues that with better co-ordinated support, increased flexibility in current systems and greater 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 German labour market.**

In order to gain an in-depth understanding of the impact of how the structural, economic, clinical and attitudinal barriers to employment affect people with schizophrenia, we reviewed previous studies (including a similar piece of research we conducted in the UK), conducted in-depth interviews with people with lived experience of schizophrenia, and spoke to professionals with expertise in the provision of health, social care and vocational rehabilitation, policy experts, and employers.

### Main findings

Schizophrenia is a severe form of mental illness that affects approximately one per cent of the German population. It is a leading cause of disability worldwide, and is often experienced co-morbidly with other chronic health conditions.

It also presents a considerable economic and social burden, not only for individuals with the condition, but also for their families, caregivers, and the health and social care systems. Often under-considered is the relationship between schizophrenia and the labour market, with a substantial proportion of the costs associated with the condition being realised in lost employment years, vocational rehabilitation services, and welfare benefits to support those seen as unable to work in the usual labour market.

Evidence indicates that many more people with schizophrenia than are currently in employment, are motivated and able to work. Indeed, echoing the evidence that work is in many cases good for health, many people with schizophrenia see a return to work as an indicator of their recovery from the illness. Participants with lived experience of schizophrenia explained how much they valued working – particularly the feeling of normality, the independence, the sense of purpose, the inclusivity, and the structure work provided them:

*Being recovered means to take part in life again.*

— Lived Experience

*Work would of course be another step to feeling more recovered. If you're in work you would always feel more recovered and normal.*

— Lived Experience

Despite this aspiration, many barriers stand in the way of people with schizophrenia seeking to enter, return to or remain in paid employment – keeping employment rates among one of the lowest of all vocationally disadvantaged groups.

### **Barriers to employment (Chapter 3)**

Schizophrenia often has considerable influence on an individual's employment opportunities. The symptoms of the illness, side effects of the treatment and the possibility of relapse may make entering or returning to work difficult. This is exacerbated by the onset of schizophrenia commonly occurring during teens and early twenties – interrupting education, early career and the transition to independent living. This can have significant implications for an individual's employment prospects, with employers searching out employees with the best job history and qualifications. Similarly, the gaps in employment history caused by period of ill health may reduce an individual's attractiveness to employers compared to other candidates.

The significance of gaps in job history will be magnified during times of national or regional financial insecurity when jobs are limited. The effect of this may be more pronounced for younger people with schizophrenia, who do not have earlier work experience to draw upon, presenting an ongoing barrier to the labour market.

*If you are young with severe mental illness then you don't get into the labour market in the first place.*

— Employment Specialist

Perhaps the greatest barrier to employment for people with schizophrenia though is other people's attitudes towards the condition. Negative perceptions in the media and society are also found among employers and colleagues who may be wary of working with someone with schizophrenia due to misconceptions about abilities or nature.

*I am very stable and I know what this illness means and that's different from what society interprets it as.*

— Lived Experience

Stigmatised attitudes can also be found among clinicians, who may not believe that employment is an option for someone with schizophrenia, and may focus their treatment only on managing clinical symptoms, rather than considering that often conceptions of recovery are much broader.

*With illnesses like depression or other anxiety disorders or with compulsive disorders I would say yes, being able to work should be a goal to work towards. With schizophrenia, I doubt that this is possible.*

— Psychiatrist

The actual health system can also have an influence here, with availability of and access to appropriate treatment across Germany varying considerably across regions. A further concern is that people with schizophrenia are ostensibly seen as a lower priority than people with other health conditions (including other mental health conditions) for some health and vocational services. Indeed, the system of insurances which funds health and vocational support in Germany may be dis-incentivised from providing some services to people with schizophrenia by the nature of the condition and perceptions towards it.

The range of active labour market and welfare mechanisms which exist to encourage and support the employment of people registered as being severely disabled is also part of this picture (though we do not know the proportion of people with schizophrenia within this category). The 5 per cent target for the employment of severely disabled people and the levy for those employers who do not meet this target, along with employment protections and the support of the 'Integration Service' (IFD), seemingly create a strong system of incentivised employment. However, the extent to which people with schizophrenia specifically are benefitted by this system is unclear, with employers seemingly more wary of employing people with severe mental illness than employing those with physical health conditions. Short-term funding of IFD services may also reduce employer confidence that they will be able to access on-going support which would enable them to better support employees and alleviate any concerns about perceived risks of employment.

### **Supporting employment through health and vocational support** (Chapters 4 and 5)

The system of dedicated vocational rehabilitation support in Germany is laudable. It is extensive and varied, paid for through insurances and supported in the Social Code. Though traditionally vocational rehabilitation services in Germany have focussed on pre-vocational training, there has been a clear shift towards a more supported employment approach - supporting people to move into work and supporting them while in work. This shift has been seen in services such as the 'rehabilitation services for the mentally ill' (RPK), and 'vocational training centres' (BTZ), and even, to a certain extent, in the approach of 'workshops for people with disabilities' (WfbM). However, the extent to which these services reflect the best evidence around achieving paid employment outcomes for people with schizophrenia is debateable - with the evidence-based Individual Placement and Support (IPS) supported employment model still a rare sight in Germany.

*There needs to be a quicker implementation of international research, for example on supported employment. Germany really is way behind on this, but there is clear empirical evidence that these programmes work, so they have to be established more quickly.*

— Occupational Therapist

*In my view in Germany we try to establish not IPS but a kind of supported employment – because clinical and work-related vocational services live in rather separated worlds and IPS integrates medical staff.*

— Employment Specialist

Though structural factors (in particular the separation of clinical and vocational services) are often cited as barriers to its implementation, the recent introduction of IPS in Switzerland may enable and encourage Germany to take steps towards implementation.

BTZ and IFD services were suggested by experts to be the vocational rehabilitation services with the most significant role in supporting people with schizophrenia into open employment. Though BTZ involves a period of pre-vocational rehabilitation, the service maintains a focus on return to work in the open labour market, and reported employment outcomes for people with schizophrenia are good. A limitation is the focus of BTZ on returning people to their retained job, or into jobs of which they have some prior experience - therefore they do not provide support for people with limited or no work experience. The IFD on the other hand provides support for job search as well as in-work support, consequently providing a model much closer to IPS. IFD services are often however hindered by short-term funding, limiting the extent to which support can be provided on an ongoing basis to both employees and employers.

Though poor access to national data on usage and outcomes limits the ability to draw together clear evidence on the use and effectiveness of such services, experts and those with lived experience highlighted their effectiveness. This was tempered by some concern that people with schizophrenia have become less likely to be placed into such services, with those with conditions such as depression and burnout – which are increasingly recognised as workplace issues – growing proportionately as service users.

This shift is also indicated by the suggestion that people with schizophrenia are increasing as participants in WfbMs. The extent to which WfbMs can be defined as vocational rehabilitation is a matter for debate – they provide a poor source of income, are rarely inclusive, and importantly, they do not reflect the aspects of work most valued by those with lived experience of schizophrenia. Fundamentally, they also rarely lead to transitions into the open labour market – with government (BMAS) figures reporting that only 0.2 per cent transition successfully. Despite these weaknesses, the strength of WfbMs provides a stark contrast to those programmes which have better labour market outcomes. WfbMs are consistently funded and very well-known – often seen as the ‘default’ option where decisions are being made on what vocational rehabilitation support would be appropriate for someone with schizophrenia to apply for.

*There needs to be a third way between the set-in-concrete institutions, like the sheltered workshops in Germany, and the very inefficient tendered programmes that only run for one year at a time. They are too weak and workshops are too strong.*

— Rehabilitation Specialist



Social Firms potentially provide an alternative employment route for people with schizophrenia. Found in-between these sheltered and supported vocational rehabilitation options, are Social Firms, they provide protected places in businesses in the usual labour market. Firms are expected to be competitive (with some support from the duty of employment quota-levy funds) with staff paid a more reasonable wage, therefore providing more of the qualities identified by participants as important elements of 'work'. Though some positive stories were shared, people with schizophrenia were also seen to be reducing as a proportion of Social Firm employees.

There are a host of barriers to accessing the vocational rehabilitation services which have the best employment outcomes. Access was found to be limited for people with schizophrenia specifically - often not seen as an obvious choice for services which seek to achieve employment on the open labour market. Also poor collection and dissemination of data on schizophrenia, service use, and employment outcomes mean that the evidence base is not there to make the case locally or nationally, and there is poor awareness of the range of possible options.

*So for someone with these problems it's usually good luck if somebody tells him or her that there is an IFD or supported employment or a good support service available in that special region.*

— Employment Specialist

One of the key criticisms of the vocational rehabilitation system in Germany is its complexity. Though the availability of a range of different service might be viewed positively, barriers exist not only in the way they are funded (with insurers sometimes unwilling to take a what they might see as risk in service provision), but also where awareness of services is low and pathways to entry are convoluted or obscured. This has led to a fragmented system in which it is difficult to identify appropriate services locally, there is considerable local variation in provision and availability, there are risks in applying for services which are not well-known (compared to WfbMs), waiting times are often considerable, and where there is little or no flexibility to move between services, even in the event of poor health.

*There needs to be more movement in the system, it's too static... there is quite a lot being offered but pathways are too cumbersome, too slow and the system is not responsive to the needs of people with severe mental illness.*

— Psychiatrist

Such barriers place people with schizophrenia - already faced with negative perceptions of their abilities and misconceptions about their personal objectives – at a further disadvantage in the labour market, facing considerable barriers to even gaining access to services which have any potential to help. For people with schizophrenia seeking to enter vocational rehabilitation, the choices are limited by the system which was designed to support them.

## Call to action (Chapter 6)

People with schizophrenia who have both the potential and the aspiration to work are not able to access the support they need. There are many areas in which change must be encouraged if we are to improve employment outcomes for this group. Improving opportunity for people with schizophrenia to access appropriate, evidence-based support is fundamental. We identify the following areas for the focus of policy makers, insurers and health and vocational care professionals:

- **Improving knowledge about what is happening, and what is working, to support people with specific health conditions.** Improving the data collection and reporting on use of vocational rehabilitation services by people with schizophrenia, and their employment outcomes, on a national level.
- **Improving the pathways to accessing appropriate vocational services.** In particular improving the pathways between health and vocational systems and services – to allow more continuous, holistic and evidence-based support to be provided. The role of the insurer also needs to be considered. We must focus on increasing the ability of people with schizophrenia to access a wider range of vocational rehabilitation options, without being limited by the process of applying for services, the cost shifting between insurers, and the stigma which predicts which vocational rehabilitation offer someone will be pushed towards.
- **Achieving a better balance between sheltered and supported employment opportunities.** Alternatives to sheltered workshops need to be strengthened so these are no longer the default option for people with schizophrenia, but instead form part of a range of alternatives which people may choose to access. Reforming sheltered workshops to improve their inclusivity, and to provide their employees with a better quality of work is also important (as seen in recent reforms to the sector in the UK). We also call for greater flexibility to allow people to move between different types of vocational rehabilitation services as reflects their progress and ability to work competitively, rather than getting trapped in one type of service. In particular, greater emphasis should be on helping people with schizophrenia transition out of sheltered workshops and into open employment.
- **Promoting the concept of employment as a recovery outcome for people with schizophrenia.** Increasing awareness among health and social care professionals that work may be a desired outcome and an important recovery marker for someone with schizophrenia, and therefore should be considered in treatment and referral decisions. The importance of returning to a normal life, which often includes work. The idea that reducing symptoms is a means to the end of a return to normal life including work needs to be reflected by the clinical and vocational worlds.
- **Supporting employers to play their part.** Raising employer awareness of what support is available for them to help employees with schizophrenia, and strengthening the support that is available. We need to change the messages

around employment of people with health conditions such as schizophrenia to enhance employer focus on what employees *can* do, as opposed to focussing overtly on what they can't do.

In the German labour market (as in others) people may perceive that for those with more severe health conditions, working in any form is an achievement in itself. Given the evidence that the prevalence of long-term health conditions within the working age population is set to increase over the next 20 years, we argue that 'any work' is not enough. 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 aspire to keep people occupied (e.g. as maybe the case in sheltered workshops), as opposed to moving them into gainful employment – and consequently supporting their health and wellbeing and movement towards recovery goals, while allowing them to contribute to the economy and society. We call for an inclusive labour market, populated with inclusive workplaces, and supported by a healthcare and welfare system which prioritises good quality work as a recovery outcome.

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# Chapter 1 Introduction

## 1.1 Objectives

We have conducted this research to examine the impact of schizophrenia on employment. In particular we focus on the individual, attitudinal and structural barriers faced by people with schizophrenia, as well as examining interventions that help people to stay at or enter into work. 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 interventions help people with schizophrenia enter or remain in employment?

We have further identified policy areas where changes should be made in order to increase the number of people with schizophrenia who are active in the labour market. We direct these messages to those working in government, and in health and vocational sectors, who we call upon to take action on these areas, and to take the steps required to improve employment outcomes for people with schizophrenia in Germany.

## 1.2 Method

To answer these research questions, we conducted a review of the academic literature, published in peer-reviewed scientific journals, as well as recent policy reports, focussed on schizophrenia and the labour market in Germany.

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 health and social care professionals, occupational, rehabilitation and vocational specialists, policymakers and employers.

Interviews were tailored in respect to the subject knowledge of each expert, but they focused broadly on the clinical and vocational implications of schizophrenia. Amongst other things, we gathered their views on the labour market benefits of changes to current early diagnosis and intervention practices, and on innovative policy and practice in Germany.

In order to gain an in-depth understanding of the structural, economic, clinical and attitudinal barriers, we conducted ten in-depth interviews with people with lived experience of schizophrenia, who were in or were seeking employment, after engagement with one of two vocational rehabilitation services (Appendix 2). The aim was to explore the experiences of

people with schizophrenia in relation to the labour market, and examine what role employers, vocational rehabilitation professionals, healthcare professionals, and others have on the working lives and aspirations 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' experiences. 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 conducted in English or German as required by participants, and were recorded and transcribed as verbatim. German transcripts were then translated into English prior to analysis. Each interview lasted between 30 and 90 minutes.

### 1.3 Structure of the report

The remainder of this report focuses on:

- **The impact of schizophrenia: individual and society (Chapter 2)** – looking at the clinical nature of schizophrenia, the way it effects the individual and society, particularly in terms of the labour market, as well as looking at recovery and the role that work can have.
- **Barriers to employment for people with schizophrenia (Chapter 3)** – exploring how the condition itself and attitudes towards it, can form barriers to employment, reducing the opportunity for people living with schizophrenia to access work.
- **Supporting employment: through treatment, rehabilitation, welfare and integration (Chapter 4)** – considering the main policies and systems which have a role in support recovery, rehabilitation, and employment, and reflecting on how well they are working in practice to support employment for people with schizophrenia.
- **Discussion of provision of and access to supported employment vocational rehabilitation in Germany (Chapter 5)** – identifying barriers to accessing the best quality vocational rehabilitation support, which might enable people with schizophrenia to enter and remain in work.
- **Conclusions and calls to action (Chapter 6)** – highlighting areas which the research has identified as crucial to address if employment rates for people living with schizophrenia are to increase.

## Chapter 2      The impact of schizophrenia: individual and society

Good work is good for health. For most people work is a normal part of life, providing at its most basic level a daily structure, activity and income. For many people with health conditions and disabilities however achieving employment can be a considerable challenge, fraught with barriers, which deny some the opportunity to experience the many benefits work can have. In this paper we explore the relationship between schizophrenia and employment. We consider the value of work to individuals, particularly in terms of their recovery, drawing on individual experiences of employment and job seeking against the many barriers to working which are reflected in the low employment rates for people with schizophrenia and the high proportions receiving early-retirement pensions. Though to some extent the barriers are found within the symptoms that an individual with schizophrenia may experience, they are also found in the attitudes held by others about the condition and how it affects ability to work. We also look at the medical, vocational and active labour market policies and systems which all contribute to whether an individual with schizophrenia will find and retain employment, before considering how these may be optimised to improve the chances employment will be achieved and retained.

### 2.1 What is schizophrenia? A clinical and social condition

Schizophrenia is a severe form of mental illness, affecting approximately 1 per cent of the world's population (Gaebel & Wölwer, 2010), and an estimated 500,000 people in Germany (Frey, 2014). The onset is often during late teens to early 30's (Almeida, Howard, Levy, & David, 1995; Mueser & McGurk, 2004) – when young men and women are likely to be making the transition to independent living, and are often in education or early career.

Schizophrenia is 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 the welfare system. Although seen as a chronic condition, many people with schizophrenia today experience both symptomatic and social recovery. Advances in treatment, social and vocational support and changes in attitudes towards mental health conditions are now enabling many people with schizophrenia to manage their condition, and live productive and fulfilling lives.

#### 2.1.1 Clinical factors: Symptoms and Progression

There is no single symptom picture that is unique to schizophrenia. Diagnosis is based on the evidence of a variety of experiences and behaviours felt by an individual, which are believed to be typical of schizophrenia.

*There are different types ... I've been doing this job for twenty years now ... and I've seen so many different progressions.*

— Occupational Therapist

As a type of psychosis, schizophrenia often involves a loss of contact with reality, including delusions and hallucinations.

*The typical onset is marked by symptoms of realisation, or rather symptoms that point towards a change in people's experiences, because that's accompanied by symptoms such as paranoia and so on.*

— Employment Specialist

Symptoms seen as characteristic of schizophrenia are grouped as 'positive' and 'negative' symptoms, with 'cognitive' symptoms sometime separately distinguished (see Box A). The progression of the condition is generally seen as occurring in three phases (National Institute for Health and Clinical Excellence, 2010). First, the prodromal phase, characterised as a deterioration in personal functioning. As this often includes harder to recognise negative and cognitive symptoms, this phase of onset may be mistaken for depression or other conditions.<sup>1</sup>

*I finished my AB<sup>2</sup> in 1982. Then I started university, but I didn't take it seriously, because I already, at that point I already had no motivation, I'm sure I was depressed. Then I did my civilian service from the end of 1983 to 1985. Then I went back to university and I had the first psychosis in 86.*

— Lived Experience

Experience of psychotic (positive) symptoms characterise the second or acute stage. Thirdly is the residual stage, where psychotic symptoms have abated but negative (and cognitive) symptoms continue. Diagnosis of schizophrenia is usually dependant on an individual experiencing more than one psychotic episode along with negative and cognitive symptoms.

*That's usually how it starts, and most of the time this is also determining the progression of*

#### **Box A: Symptoms of schizophrenia**

*Positive symptoms might include:*

- Delusions;
- Hallucinations (auditory, sensory and/or visual);
- Disorganized speech - as a manifestation of thought disorder;
- Grossly disorganized behaviour (e.g. dressing inappropriately, crying frequently, impulsivity) or catatonic behaviour.

*Negative symptoms might include:*

- "Flat affect" (lack of facial movement, talks in a dull or monotonous voice);
- Lack of pleasure in everyday life (anhedonia);
- Low motivation or lack of ability to begin and sustain planned activities (asociality & avolition);
- Speaking little, even when forced to interact (alogia).

*Cognitive symptoms might include:*

- Thought disorder and poor "executive functioning";
- Trouble focusing or paying attention;
- Problems with "working memory".

<sup>1</sup> <http://www.nimh.nih.gov/health/publications/schizophrenia/index.shtml>

<sup>2</sup> Abitur (German secondary school final examination)



*the illness, i.e. that the mental capacity to cope is reduced, resilience to stress is reduced, flexibility in daily life is also reduced, so that things like switching between several tasks or multi-tasking is not possible anymore. In summary, a lot of things that have to do with coping in everyday life.*

— Psychiatrist

Negative and cognitive symptoms tend to be more persistent than positive symptoms. They 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).

Though many people with schizophrenia will only experience a single psychotic episode (Alvarez-Jimenez et al., 2011), many others will relapse, sometimes multiple times. Relapse will often result in a period of hospitalisation, with frequent in-patient stays endangering social and occupational integration, reducing the ability to work and social participation – thus affecting quality of life (Zeidler, Slawik, Fleischmann, & Greiner, 2012). Some experts identified severe cases where a chronic deterioration occurs and symptoms remain after each relapse.

*The people that we work with [in the hospital], there is a negative selection so to speak, people who come to us have had frequent relapses and with every relapse a little more of the symptoms have remained. This means, what we see is the classic chronic progression, which is not necessarily the course for all patients, but those are the ones who come to us.*

— Rehabilitation Specialist

### **2.1.2 Social factors: Inclusion and employment**

The symptoms of schizophrenia are only one part of the picture in terms of how an individual may be affected by the condition. The condition has implications for a range of health and social outcomes.

People with schizophrenia have considerably higher levels of mortality and morbidity than the general population (De Hert et al., 2011) – reducing an affected individual's life span by on average ten years. A major driver of lowered life expectancy is the presence of co-morbid physical health conditions (Hewer & Rössler, 1997; Hewer, Rössler, Fatkenheuer, & Löffler, 1995), attributed in part to the presence of modifiable risk factors, such as smoking, poor diet and weight gain (the latter being a side effect of many antipsychotic medications) (Connolly & Kelly, 2005). A health profile of people with schizophrenia in Germany identified high rates of smoking (58 per cent), illegal drug addiction (15 per cent), overweight/obesity (33 per cent) and hypertension (18 per cent) (Papageorgiou, Cañas, Zink, & Rossi, 2011). Higher rates of suicide than found in the general population also contribute to lowered life expectancy (Pompili et al., 2007) – in Germany this is estimated to be 35 per cent (Bebbington et al., 2005), with rates even higher among men (Saha, Chant, Welham, & McGrath, 2005).

People with schizophrenia have a higher tendency to experience certain types of social

exclusion than the general population, such as homelessness and imprisonment (Bebbington et al., 2005). Not having a stable home was noted as being a critical factor in recovery.

*One very important point is if the person has no place to live of their own. There needs to be a suitable living structure, a suitable living environment, which has a mobile therapeutic concept, and another point I find very important is daily structure/work. These are the two central points which I think are important.*

— Rehabilitation Specialist

In Germany an estimated 8.4 per cent of people with schizophrenia have been homeless and 7.1 per cent imprisoned. Though high, levels of social exclusion have been identified as higher in the UK (Bebbington et al., 2005). An estimated third of people with schizophrenias in Germany live alone (Bebbington et al., 2005; Papageorgiou et al., 2011), though they are more likely to be, or to have, cohabited with a partner than found in the UK (Bebbington et al., 2005).

People with schizophrenia are very likely to experience unemployment – internationally they encounter one of the highest unemployment rates among all vocationally disadvantaged groups (Kilian & Becker, 2007). This is despite the evidence suggesting that a far greater proportion of people with schizophrenia are able to work (Marwaha & Johnson, 2004), and want to work (Mueser, Salyers, & Mueser, 2001).

The employment situation in Germany for people with severe mental illness is acknowledged as extremely unsatisfactory (Aktion Psychisch Kranke, 2007). Though official figures are not available, taking data from a range of studies over the past ten years allows us to surmise an employment rate for people with schizophrenia of between 19 and 26 per cent (Haro et al., 2011; Marwaha et al., 2007; Papageorgiou et al., 2011). This is against high employment rates generally in Germany – with unemployment currently around 5 per cent (August 2014), falling from a peak of 13 per cent in 2005.

Along with those who are officially unemployed, people with schizophrenia may be outside the usual labour market, for example working in sheltered workshops is not always recorded in official employment figures (Doose, 2012). One study showed that as many as 38 per cent of employed people with schizophrenia were in sheltered or voluntary roles with nominal if any salary<sup>3</sup>. Rates of sheltered employment for people with schizophrenia are high in Germany in comparison to some European countries (e.g. the same figure was 5 per cent in the UK and 18 per cent in France) (Marwaha et al., 2007).

It is also common for people with conditions such as schizophrenia to have their salaries supplemented by payments to compensate for their 'reduced earning capacity'<sup>4</sup>, enabling

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<sup>3</sup> These figures must be taken with caution, not only due to the small sample size, but also due to the considerable variation in employment rates between the three German sites, e.g. the 'total working' is 23.9% in Leipzig but 60% in Heilbronn. This particular fact reflects the fact that Heilbronn had a higher number of patients currently in placements, but mostly in supported work activities paid below 50% of the minimum wage.

<sup>4</sup> <http://www.working-in-germany.com/pension-for-reduced-earning-capacity-0076.html>

them to work less hours, or to receive a disability pension allowing early retirement. Rates of people with schizophrenia in these categories have been identified as being higher than the rates of those in normal paid employment (Marwaha et al., 2007; Papageorgiou et al., 2011).

*I really wanted to tell you about a friend of mine, a young woman, she's about 40, who also suffers from a schizophrenic condition, but she's the only one I know who is still employed in the regular labour market. She works reduced hours, has severely disabled status and her employer has accepted that. But she's really the only one that I know. If I think about my own patients, well all of them are either in a sheltered workshop or a day care centre or in minor additional earning jobs and either receive a pension or basic social care.*

— Social Worker

The age of onset of schizophrenia presents a particular problem in terms of employment – with many people becoming ill before commencing or during their university course – as reported by a number of lived experience and other participants, or when commencing their career. The extent of prodromal symptoms may have been a barrier to employment at an even younger age – with some evidence indicating that employment rates among people with schizophrenia decrease even before the first diagnosis (Agerbo, Byrne, Eaton, & Mortensen, 2004; Greve & Nielsen, 2013).

### **2.1.3 Costs of schizophrenia**

The costs to society of schizophrenia are also significant. It is one of the most expensive mental health conditions (Rössler, Salize, & Knapp, 1998) costing Germany billions of Euros annually (Konnopka, Klingberg, Wittorf, & König, 2009). Per patient, per year, costs are estimated at €11,304 from the insurer payers' perspective (i.e. health insurance, unemployment insurance and the pension fund) (Frey, 2014) and €20,609 from the societal perspective. In total this represents a cost of between €9.63 billion and €13.52 billion annually (Frey, 2014). This includes direct medical costs, direct non-medical costs (administration costs, sick-leave pay, travel expenses), and indirect costs (including lost productivity caused by absence from work, disability, and premature mortality).

Along with the direct costs of in-patient medical treatment, and the costs of other care (including community care and informal family care (Frey, 2014)), there are many indirect costs relating to the above factors – difficulty in education, dependency, physical illnesses, prison, and homelessness (NAMI, 2008), as well as costs related to employment and unemployment (Andlin-Sobocki, 2005; Frey, Linder, & Stargardt, 2012; Huxley & Thornicroft, 2003; Kilian & Becker, 2007; Social Exclusion Unit, 2004).

Mental and behavioural disorders are responsible for the greatest number of lost workforce years in Germany (763 per 1000 in 2008), with schizophrenia and relating disorders accounting for 112 lost workforce years per 1000 years<sup>5</sup>. The costs relating to lost productivity and sickness absence due to mental illness have been increasing (Kilian & Becker, 2007) – a considerable concern given the estimate that 86,000 years of employment

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<sup>5</sup> Lost workforce years in 1,000 years for Germany. Available from: <https://www.gbe-bund.de/>

had been lost as a result of schizophrenia (Von der Schulenburg et al., 1998).

*We notice, that mental health problems become an ever growing concern, i.e. there are more and more people with conditions like that, whether that be schizophrenia or other conditions, like burn-out syndrome etc., that all have to do with mental health. This will gain even more importance in the future, we can already see that today.*

— BMAS Civil Servant

Early retirement and receipt of the disability pension is another considerable cost. Mental illness is the leading cause of early retirement in Germany – almost 1 in 4 new cases of eligibility for the early retirement pensions are related to mental illness (Kilian & Becker, 2007). Mental illness is also associated with earlier retirement than with other diagnoses - the average age of entry for pensions (through Statutory Pension Insurance) due to diminution of ability to work is 52 years. For those with mental health condition it is 49 years old, and for those with schizophrenia, schizotypal and delusional disorders it's 41 years old<sup>6</sup>. Out of the 4,493 per 100,000 people aged under 30 who received a new pension because of diminution of ability to work, a quarter had a schizophrenia related condition – by far the biggest condition group.<sup>7</sup>

## 2.2 Recovery, inclusion and employment

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).

Both the illness, and the societal implication of having it are experienced differently by different individuals. Many people with schizophrenia experience substantial recovery (Lysaker, Ringer, Maxwell, McGuire, & Lecomte, 2010), going on to live productive and fulfilling lives (National Institute for Health and Clinical Excellence, 2010). This knowledge represents a considerable shift in the concept of progression and recovery in schizophrenia over the last few decades (Lysaker et al., 2010). As late as the mid-90's it was considered that a return to complete functioning might not be possible (Lysaker et al., 2010), but evidence has fast grown indicating that the long-term course of schizophrenia is more favourable and more variable than had previously been believed, even where treatment had been limited (Ciompi, 1988).

In this section we discuss recovery, and particularly the relationship between employment and recovery for people with schizophrenia, before going on to consider whether different types of employment have a closer association with recovery.

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<sup>6</sup> Average entry age into pensions because of diminution of ability to work in the Statutory Pension Insurance. Classification: years, Germany, sex, 1. diagnosis (ICD-10), pension fund organization. Available from: <https://www.gbe-bund.de/>

<sup>7</sup> Statutory Pension Insurance, new pensions because of diminution of ability to work (number/per 100,000 actively insured persons). Classification: years, Germany, age, sex, 1. diagnosis (ICD-10), pension fund organization. Available from: <https://www.gbe-bund.de/>

People with lived experience of schizophrenia provided in interviews their stories of personal recovery – explaining their transition from experiences of psychosis to the happy, healthy, productive lives they now have. For example:

*I was too ill and I just couldn't manage it intellectually. At the beginning, because everything was broken, like a short-circuit in my brain, I could only form very simple sentences and my linguistic abilities were all gone and I had to work at it for years for it to get better again. ... Well, in 22 days I'm celebrating my 25th anniversary in the company.... Nobody thought that I'd come back after the retraining period [laughs], they told me that back then.*

— Lived Experience

A chronic progressive course is estimated today to develop in between just 10 to 30 per cent of patients (Gaebel & Wölwer, 2010). Remission of symptoms varies from one individual to the next – it is estimated that between a quarter and a third of people diagnosed with schizophrenia experience a recovery from psychotic symptoms, while a similar proportion will experience considerable improvement in social functioning (Ciompi, 1988; DGPPN, 2014; Mueser & McGurk, 2004; Rössler, Salize, van Os, & Riecher-Rössler, 2005).

*There are different progressions, of course... so there is the more chronically-progressive course of schizophrenic psychosis, there are rare cases where people make a full recovery, but more often, that's not the case.*

— Employment Specialist

Symptom remission and the discontinuation of medical treatment are seen as just part of what might be meant by recovery. Today recovery is seen as a more malleable concept, centred around what the individual sees as important in terms of their ability to function and participate in society, and to live a meaningful life within the limits of the condition (Shepherd, Boardman, & Slade, 2008; The Schizophrenia Commission, 2012) – whether characterised by independent living, being employed, or entering into peer relationships (Lieberman, Kopelowicz, Ventura, & Gutkind, 2002). It is often characterised by an individual gaining back control of their lives (Spaniol, Wewiorski, Gagne, & Anthony, 2002). When asked about the most important outcomes when treating someone with schizophrenia, experts we spoke to discussed not just symptoms, but also social participation and having a meaningful personal life, social and work integration, including avoiding poverty, having a high quality of life, and general happiness.

Participants with lived experience were asked about their concept of recovery – what it meant to them.

*Being recovered means to take part in life again, not to be isolated, having active friendships and people visiting and meeting up with friends and also to be able to perform in a job and to have a positive perspective on life.*

— Lived Experience

*Well, in the past 10-12 years, I'd have to say work. To have a task during the day. Then also*

*friends and family, social contacts with friends, meeting up and doing things together. Financial independence also in recent times, being able to live my own life, more or less, you know. That I can afford things, sometime, can go on holiday, can afford to smoke - only joking... But, yes, that I simply feel integrated into society again, that I can indulge in my hobbies.*

— Lived Experience

Many previous studies have explored what factors are associated with improved recovery outcomes. Employment, marital status and having had access to comprehensive mental health services, including early intervention, are frequently raised (Lieberman et al., 2002; Rosen & Garety, 2005; Spaniol et al., 2002). Alongside this are a number of other social-demographic and clinical variables, for which results are less conclusive. These include: attaining higher levels of education, being female, better pre-morbid functioning, having no family history of schizophrenia, being an older age at onset, and increased social contact (Rosen & Garety, 2005). Engagement with services such as skill development interventions, supported employment, education and housing have also been identified as having this association (Spaniol et al., 2002). This has led to the conclusion that it is a range of circumstances subsequent to onset of the condition, including adequacy of treatment, adverse life events, employment, social support and stress, which might influence different recovery outcomes (Rosen & Garety, 2005).

Becoming ill again or relapsing (given the often fluctuating nature of the condition) is not necessarily a barrier to recovery or living a normal life, including work – for example, lived experience participants discussed returning to work after repeat periods of ill health, and returning to full work-ability.

*That was the time where I was under a lot of stress, and yes, I do think my ability was limited then. But, even if I say so myself, I think I can now work normally.*

— Lived Experience

Being employed is often associated with recovery – contributing to fulfilling life, and helping people to regain a sense of meaning (Shepherd et al., 2008). All participants with lived experience of schizophrenia spoke of the important role of work to their recovery journey.

*Work would of course be another step to feeling more recovered. If you're in work you would always feel more recovered and normal.*

— Lived Experience

The benefits of employment for someone with schizophrenia go beyond the financial benefits of earning a wage – they include improved health and wellbeing (including suicide prevention), social inclusion and integration (Aktion Psychisch Kranke, 2007; Marwaha & Johnson, 2004; Pompili et al., 2007; Waddell & Burton, 2006). Interviews with both lived experience participants and other experts were clear that work was highly desirable, valuable and beneficial for people with schizophrenia.



*Work is a very important factor in a person's life, at least in our culture, and people with schizophrenia, of course, feel excluded if they cannot take part and contribute to work life in society.*

— Employment Specialist

*There is no better therapy than work, that applies to healthy people as much as to people with any kind of disability and I really can say that here, also from my experience - I had been working on the psychiatric ward in the local hospital here, and I can't stress that often and loud enough, how important that is as "therapy", work itself.*

— Employer, Social Firm

This research reaffirmed the wealth of studies indicating that work is often beneficial for people with schizophrenia and has an important role in recovery (Bell, Fiszdon, Greig, & Bryson, 2005; Bell, Lysaker, & Milstein, 1996; Bryson, Lysaker, & Bell, 2002). The relationship between work, health and functioning was examined in the EQOLISE study, undertaken in cities of six European countries (including Ulm, Germany). They found participants with schizophrenia who had been recently employed or were still in employment had improved global functioning, fewer symptoms, less social disability and were more likely to be in remission in the subsequent six months, than those who had not (Burns et al., 2009). Other studies have identified associations between working and symptom remission (Schennach et al., 2012), and between working and reduced use of health services, including fewer medications (Drake, Xie, Bond, McHugo, & Caton, 2013). Some studies have been able to demonstrate improvements are related to employment – for example, measuring pre and post intervention functioning levels in employed and unemployed groups found improvements in functioning, quality of life and psychological well-being as a result of work (Watzke, Galvao, & Brieger, 2009) – showing clear links that being employed can have positive outcomes for health for people with severe mental illness.

The relationship between health and employment was recognised by expert participants:

*Whenever people are engaged in meaningful work that lowers the risk of relapsing. There is a very clear correlation, negative correlation, between unemployment and mental illness. No other job causes that much mental illness as the "job" of unemployment.*

— Occupational Therapist

*As soon as the illness is not in an acute phase anymore, of course, work helps with reintegrating into life and to regain health. Sometimes that has to happen very slowly and has to be increased step-by-step, but it certainly is a contributing factor. We ask all our participants one year after the training, how their health has been developing and most of them say that their health has improved.*

— Employment Specialist

Some experts participants, including those with lived experience of schizophrenias, were more wary of the role of work than others:

*It [work] can help, if it gives the affected person a structure in their life, also the social integration, but it can also be harmful, if the work is very stressful and straining, this will rather aggravate the symptoms. So, work can be beneficial as well as harmful for people with schizophrenia. It depends on the circumstances.*

— Psychiatrist

*I think, when everything is going well that work has a stabilising effect, but when it gets very stressful then I have to be careful not to get ill.*

— Lived Experience

*Yes, I used to work in the catering business, with [company name] and I got into a crisis there, because there was too much stress*

— Lived Experience

The inclusion of vocational rehabilitation as a treatment goal of the DGPPN guidelines on the treatment of schizophrenia (DGPPN, 2006) as well as on psychosocial interventions for those with severe mental health illness (DGPPN, 2014), along with the call to prevent and reduce the social consequences of schizophrenia, indicates there is widespread appreciation of the importance of work among healthcare professionals. Expert interviewees felt that whilst healthcare professionals appreciated the importance of work and saw a role for it in the recovery of many individuals, there was some concern over whether it was seen as important enough, particularly in relation to symptom control, as demonstrated by these differing viewpoints

*I think there is too much of a focus on symptoms and too little focus on work participation, on labour market integration and the work role. I think there is a very very moderate move in the right direction.*

— Psychiatrist/Academic

*Well, it's generally the case with mental illnesses that part of the treatment should work towards that person being able to live independently again and work is, of course, part of that. It's debatable whether this is always possible with schizophrenia, but that shouldn't be the main goal. The main goal should rather be that the person can live a life that is relatively free of anxiety, where the daily life is not too affected by the symptoms. I think this should be the priority. Being able to work is relatively rare with schizophrenia.*

— Psychiatrist

For those with lived experience of schizophrenia interviewed in this study, the value of work was clear and emphasised by all.

*I have very good experiences every day when I'm in my daily work routine.*

— Lived Experience

The reasons work was so highly valued were explored – Box B provides a summary of the main reasons identified from the interviews – these are examined in more detail below.



Earning an income is an important reason that many people want to work. Indeed this was reflected in interviews, with being paid mentioned by several participants.

Money was clearly only one aspect, and not the primary reason why work was felt to be important. For example, one interviewee reported that after retirement she hopes to keep in touch with the workplace, less for the money, but to be able to 'hang on for a bit', while another rated 'money' in third place, after the 'work environment' and 'having taxing work.'

Earning money to allow goods to be purchased was mentioned, but more often, the value of 'being paid' was linked to being financially independent – in particular no longer being on welfare benefits or feeling under obligation to the state.

*Yes, money of course, that is quite important to me, also that I'm... well, I'm not paid that greatly, but it is really important to me that I can earn my own living, that I'm not dependent on benefits and that's also an incentive.*

— Lived Experience

*I always found it very unpleasant having to receive unemployment benefits or social benefits and in that way having some kind of obligation to the job centre and so on. I'd been feeling constantly under pressure, put under pressure and now I can carve out my own life.*

— Lived Experience

*Today I tell myself, I don't give a damn what I earn. It's still more than benefits. I have a job. I can contribute.*

— Lived Experience

The link between earning money as a means to independence might also be seen as earning money to achieve not only independence, but also to contribute to society.

*Work means that I'm able to perform and that I can show that, that I'm being paid for it and that I can therefore afford to buy myself something special, that I am able to function like a normal – so to say – human being and can contribute to society.*

— Lived Experience

#### **Box B: What do participants value most about work and working?**

- **Independence** – earning an income and therefore being less financially dependent on society, and well as being empowered to be an independent individual, contributing to society.
- **Normality** – being treated, and feeling like a normal, equal, member of society, no different from anyone else.
- **Sense of purpose** – contributing to society, and building confidence and self-worth through knowing that you have the ability to do something useful.
- **Structure** – not only in terms of structure through the day but more importantly being able to realise the value of holidays and time off through having structured working time.
- **Supported and included** – having colleagues with whom there are opportunities for socialisation and who offer them support.
- **Enjoyment** – of working and of participation in society

Ideas around independence and contributing to society are tied up with the feeling of being “normal”, included in mainstream society, and participating like everyone else despite having a health condition.

*One thing that I've learnt is people [with schizophrenia] thrive on as much “normality” as possible.*

— Employer, Social Firm

*Simply participating in a normal society, that's something I really enjoy, that's important and yes, well, really great, for me as someone with an illness. It is the essence of life, that I don't have to say, well, like they used to have these signs in front of shops “no dogs”, so they had to stay outside. That you don't have to stay outside, that you are allowed to take part, you can be who you are, different, and still join in. You don't have to be exactly like the others*

— Lived Experience

Themes around both contributing to society and self-fulfilment were raised – particularly how meaningful work gave a sense of purpose, and helped build confidence and was marked out as having positive implications for health and wellbeing.

*A lot, a great, great deal. Purpose, purpose in life definitely and also fulfilment, having fun, being useful, yes, just being useful in society, things like that.*

— Lived Experience

*First of all, earning money, of course, and then it's of course also good for your self-affirmation, that you can show what you can do, that you're contributing in some form.*

— Lived Experience

*It is important for me to work, because I want to participate in society according to my own self-value and I want to contribute to society and I don't want to lie around in a hammock somewhere.*

— Lived Experience

*Work has had a very positive effect, because I just realised that there are things that I do really well. That I can accomplish things, that I can be successful, that has given me positive affirmation, and it has made me more self-confident and it has also lead to me being able to draw boundaries a bit more and that, in turn, is also good for my health.*

— Lived Experience

The structure offered by work, and having daily and weekly routines were seen as important, again emphasised by both lived experience and other expert participants.

*It fulfils me, it also gives structure to my day.*

— Lived Experience

*A little bit of work, maybe two or three hours, three days a week, that's quite good and that*

*helps to keep structure in your day and to take part in a day*

— Lived Experience

For experts, the emphasis was on the stabilising effect of structure for an individual.

*I've come to the conviction that a sensible daily structure or work are as important as the right medication.*

— Rehabilitation Specialist

*I'm absolutely convinced that work is important for stabilising a patient and, well, work can also offer a degree of distraction for many people, for example, if they are under a lot of pressure at home, they like going to work, because they get somewhat distracted from their private problems.*

— Employment Specialist

For those with lived experience, emphasis was both on the value of having a structured day, as well as the way that having structured a day allowed them to have unstructured time – that 'free time' out of work to spend at leisure on weekends, holidays and evenings was only a possibility if you also have 'work time'.

*I think the best thing is really to be able to work, then you look forward to going home at the end of the day, and the weekend. Yes. That's your purpose in life*

— Lived Experience

*You leave the house in the morning, you get back and you have... you value... also your spare time, when you also go to work. I really enjoy that every day.*

— Lived Experience

One participant suggested that upon retirement, she would seek volunteering opportunities, to ensure she could retain structure in her days.

*That I keep a structure to my day and not just laze away the days, sleep till afternoon, do you see what I mean, just to have something.*

— Lived Experience

The roles of colleagues in providing a social aspect to work as well as being a source of support were emphasised. Participants spoke of the relationships they had built and how much they valued them, and the importance of being part of a team.

*The most important aspect in a job? Hmm... the interpersonal relationships, that we listen to each other and talk to each other and help each other. And we're just there for each other and you're not alone.*

— Lived Experience

*Well, one thing that would be important is to get adequately paid and to get on well with*

*colleagues and that that may lead to social contacts.*

— Lived Experience

An important observation is that the value of work identified by someone with schizophrenia simply reflects what all people would expect and desire in their lives. It is noteworthy that certain aspects of work received greater emphasis by lived experience participants than you might normally expect to hear. In particular, the importance of the daily and weekly structure that work provides.

*I do think that fundamentally, structure, knowing, purpose, what gives your life a purpose, to structure your day, that you're needed, that you meet people, that you are able to contribute, that, at the end of the day, you say what you've managed to do today, that simply creates a basic form of satisfaction and security and I have to say it again, that's the same for both the ill and the healthy.*

— Employer, Social Firm

### **2.2.1 Defining employment**

Previous research suggests that different types of work may vary in value as regards supporting health and wellbeing. Though work is generally seen as better for health and wellbeing than unemployment (Waddell & Burton, 2006), commentary increasingly focusses on whether this effect varies with different types of work – in particular, the evidence that jobs of poor psychosocial quality are in fact worse for health than unemployment (Butterworth et al., 2011). Some interviewees highlighted the importance of fulfilling work, reflecting an individual's skills and interests, as an aid to recovery for someone with schizophrenia, while some conceived that any job, good or bad, has value that should be recognised for this vocationally excluded cohort.

*I would say, for many people with mental health issues, it's true that a middle-rate or even a poor job is better than no job, because being unemployed is the worst in the long term.*

— Employment Specialist

All lived experience participants were in or had undertaken some form of open employment since being diagnosed with schizophrenia, with one exception, a young man who had been unemployed for three years since completing a workplace apprenticeship at an advertising agency. While some worked full-time, others only worked a few hours a week. One participant worked in a voluntary role. Participants tended to have had a long tenure at work, with the longest being 22 years. All participants seemed extremely satisfied with their roles

*Well, that's actually my ideal job, the one I'm doing at the moment.*

— Lived Experience

Participants reflected previous research, identifying the importance of finding a role that 'clicked' with their abilities and strengths (Krupa, 2004).

[Interviewer:] *And what is the best experience you've ever had of work?*

[Participant:] *That I've ended up here and that I'm allowed to work here.*

[I:] *And why is this here your best experience?*

[P:] *Well, this is my profession. Cooking, and if it's only prep-work, that fine. I've always loved doing that. And that's why I feel, let's say, a bit more highly regarded.*

— Lived Experience

In terms of the 'type' of the job, there was no clear indication that any type might be better suited to someone with schizophrenia. In previous research, people with schizophrenia in Germany have been found to hold various positions – including professional and associate professional, skilled trades, and customer service occupations, with elementary occupations and sheltered or voluntary work the most common (Marwaha et al., 2007). Participants in this study worked in various areas, including administration, sales, technical professions, catering, commerce and advertising.

*Areas of work, well that's also with someone who doesn't have any mental illness. I always think it's down to what kind of resources you have. Of course you have to assess that, there's differences, some people are better suited for practical tasks, others more for theoretical areas.... You have to know where the abilities of the individual person lies, what are their personal resources and then you have to make sure you use these effectively.... You know, there are highly academic people who become schizophrenic, or there's also tradesmen who get it, it's completely independent from their IQ or their qualification.*

— Employer, Social Firm

*We can't generalise here what [job] would be most suitable. That will depend on the individual case. It also depends what the individual person wants to do. In many cases, these people are trained professionals, they weren't born with schizophrenia, but a lot of them had been working and then got ill so they already have professional training.*

— BMAS Civil Servant

Not only were the industries different, but the nature of the job, for example, while some of our participants relished working with other people, others preferred to work alone, some were very concerned about having any time pressure, others felt they could manage it and sought a challenge.

*There are no general rules – what is too simple for one person, can be too demanding for the other, what one sees as stress, the other sees as positive challenge.*

— Occupational Therapist

This runs counter to the tendency identified in other studies to assume that unskilled, low responsibility roles, with limited customer interaction are the most appropriate job types for people with schizophrenia (Baron, 2000; Krupa, 2004; Scheid, 2005). This notion might restrict the number of jobs in the open labour market seen as 'available' to someone with the condition (Marwaha et al., 2007), and may encourage a view that employment outside of the open labour market, e.g. in sheltered work, is a more appropriate work option. Most

participants were keen to dispute this – seeing such assumptions as stifling abilities and potential.

*It's wrong to offer only simple tasks "because of the illness". One never knows unless the person can find out themselves and be cared for while doing this.*

— Occupational Therapist

*Well, to be honest with you, I got along fine really wherever I was. I had a number of workplaces, but not because I was unsteady.*

— Lived Experience

Some experts reflected that very senior or demanding jobs might not be appropriate, as they might be too stressful. This reflects concern raised in previous research around 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). Some experts felt that in many cases a return to work at the same level of seniority they had had prior to becoming ill may not be advisable at least at first, with some suggesting that period of stabilisation at a slightly lower level might be beneficial.

*If they had a position with a lot of responsibility before they became ill... then it might be necessary to let them re-enter one or two steps down from that, in order for them to stabilised and then they can take on more responsibility again later on.*

—Employment Specialist

However, it was noted that observation required caution, as the 'downgrading' of the role might create considerable disappointment.

*There are people who have high professional qualifications, who have a degree, who have done high-level jobs. And if they experience some kind of downgrading in their job, that's often very painful for them. For lower-level workers that's not such a big problem, but for graduates it is often difficult and can bring about a crisis, when they realise that they cannot continue working on the same level...*

—Employment Specialist

It is not clear that making a judgement of whether a type of job would be 'too stressful' for someone with schizophrenia is valuable – indeed, previous research has found individuals often have considerable capacity to manage workplace stress and avoid relapse. Though many aspects of the work environment might be identified as sources of stress, not all stress is associated with emergence of symptoms, with certain specific triggers seen as problematic (e.g. interpersonal conflict) (Krupa, 2004).

*Another thing that helps me that I work alone, because there is no stress with other people, so we're a two-man company and my boss is a free-lancer working somewhere else and so there is no interpersonal stress at all.*

—Lived Experience

It is therefore likely that it is the individual working environment rather than a 'type' of job, which might be problematic.

Lived experience participants showed considerable awareness of their condition and what aspects of work might affect it, and made individual decisions about what would be appropriate for them. For example, one participant spoke about leaving her work in the caring professions as she feared it would be too emotionally challenging for her.

*That's why I thought it would be good for me to go into commerce, because I wouldn't be in such an emotionally demanding environment.*

— Lived Experience

The above evidence demonstrates that schizophrenia does not present a barrier to employment generally, nor is it inherently a barrier to a specific type of job. It is the individual's skills, interests, and abilities, as well as the quality of the job, which dictate an appropriate job. Insight into the nature of their condition and what might trigger ill health appeared to be a crucial factor, allowing participants to manage their health regardless of the type of job. In several examples, there was a preference for working less than full-time hours, though again this was very much based on the individual's context and need.

A further issue in Germany is whether 'work' is in the open labour market, or sheltered conditions – such as the WfbM. Germany has a strong system of sheltered workshops, providing the main alternative to open employment for people with severe disability. Many people with mental health conditions work in this setting – estimated 20 per cent of workshop participants<sup>8</sup>. A different type of sheltered employment, the social firm is also relatively common in Germany, these operate under a different model, and are more likely to pay employees a more competitive rate (more information on sheltered workshops and social firms can be found in Chapter 4 and in Appendix 3).

The value of protected work rather than open work is often debated. From an inclusion perspective, working in the open labour market is often seen as ideal. However, reintegration into open, competitive work is not seen as an appropriate aim for all people with severe mental illness (Bachrach, 2000; Reker & Eikelmann, 2004). 'Appropriate' work might therefore be seen as a spectrum, with different individuals sitting in different places, depending on factors such as illness severity, functioning and motivation.

*There isn't THE definition... work has to be defined in several ways.... So, gainful employment is work in the narrower sense, then there's work in the broader sense, which includes, for example, sheltered work.*

— Occupational Therapist

On this spectrum, the option for not being in work must also be included for those with the most debilitating conditions – with one carer suggesting that sheltered work was not always appropriate.

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<sup>8</sup> <http://www.bagwfbm.de/page/25>



*Hmm, maybe one or two hours, something without any time pressure and really something very simple, maybe packing or something, but then he would have to have someone sitting next to him to see that he sticks with it, I think that would even be difficult in a sheltered workshop.*

— Carer

Even with the experience of this carer, they were still clear that this was not the situation for all people with schizophrenia, and that this would differ drastically for different individuals with schizophrenia, with work on the open labour market being a viable outcome for others.

*Well, that always depends on the person.... With a different kind of progression maybe that's different. Sometimes people tell us in the carer support group that someone is back in work, full-time or part-time, if the medication is right and it's not such a severe form of the illness. You know, there are different kinds of schizophrenia.*

— Carer

As discussed in Chapter 3, where we look at barriers to employment, different perspectives on what someone's ability to work or what type of employment outcomes they should be seeking might become a barrier to what support they access and what type of 'work' they enter. Even in this small sample of expert participants, views on what was appropriate 'work' and work related services varied considerably. For example, those who perhaps more often experienced people when they were less well recovered (e.g. at discharge from hospital or being assigned a guardian), were more inclined to see sheltered workshops as the most likely option, than those who were more directly involved in other vocational rehabilitation services.

*There's the sheltered workshops, I like referring people there, I have to say.*

— Social Worker

The extent to which recovery requires open employment as opposed to other forms of occupation (i.e. sheltered or voluntary) is a subject for debate. Though much of the research regarding employment and schizophrenia is focussed on open employment outcomes, some suggest that integration into sheltered work or further rehabilitation should also be seen as positive rehabilitation outcomes (Schrang & Slade, 2007).

No participants in this study were employed in sheltered workshops (though some may have been employed via a social firm), making analysis of the respective benefits of open and sheltered employment difficult. There was little indication however from interviews that sheltered work was seen as beneficial for recovery in the same manner as open employment.

*People regain the most self-esteem best when they get into usual employment, where they work with fair and open-minded people. To be, as the word 'inclusion' says, the same and to receive the same recognition as people without disabilities. Of course, that's not always possible, that's why there are sheltered workshops for people with disabilities, and they are*



*also a very important area.*

— Employer, Social Firm

As highlighted above, lived experience participants identified factors which they found valuable about work (Box B, page 13). Considering these factors as markers of 'what makes work valuable', it might be assumed that sheltered work is seen as intrinsically less valuable to participants. Sheltered workshops, like open employment, provide structure, will involve colleagues and therefore socialisation and mutual support, and to some degree may provide a sense of purpose as participants are occupied with a meaningful task – all of which were highlighted as valuable features of work.

*Many people cannot achieve that [open employment], they then depend on sheltered workshops, but what they are offered there is also work, because work in the general sense is any activity that produces an economically usable result.*

— Occupational Therapist

However, sheltered work (as well as voluntary work) does not provide competitive remuneration, with would allow financial independence – something emphasised by all participants as important.

*Financial independence through a “normal job”, so a job that’s paid normally and not the sheltered workshops, where I think you’d find it difficult to manage financially.*

— Lived Experience

*I think voluntary work is just as valuable as paid work, but the difference is, the voluntary work is, well, what am I saying... it is very important, but I prefer to work and earn money so that I can support my family.*

— Lived Experience

*Voluntary is all good and well, but they are not going to pay for my pension later, are they?*

— Lived Experience

*The starting point has to be common gainful employment, that needs to be defined and that should be the goal, this is normal work that a person can live on, i.e. where the person earns a salary which covers a substantial part of their living expenses.*

— Occupational Therapist

The extent to which a sense of purpose might be achieved through working in sheltered workshops is also less clear – with there seeming to be less intrinsic value attached to it.

*In my opinion, the acknowledgement is much bigger if you work on the regular labour market.*

— Lived Experience

The sense of normality achieved for those working in the open labour market may not be felt

to the same extent by those working in sheltered settings. The protected nature of such work was raised as a concern for some, who felt they may not be sufficiently 'inclusive' in terms of broader societal integration.

*I'm sceptical about all these. We call them, "special worlds" where you separate people from the usual way people live, and the usual places that people live. We have this new expression 'inclusion', and to me often it's not really inclusive.*

— Employment Specialist

Though sheltered work does not appear to fit the criteria provided by participants for valuable work, expert participants were keen to emphasise their role in engaging some people with schizophrenia in work. There was the suggestion that in some cases people might even opt for sheltered workshops as their preference.

*I do know people who say "For me I do need a sheltered workshop, I don't want to go to a usual firm, I have experienced this before and I do want to have my special world, with my colleagues that understand, that have schizophrenia like I have."*

— Employment Specialist

What came across most strongly was what 'work' is valuable must be defined by the individual. Individuals with schizophrenia should be supported to choose and enter into the most appropriate option for them. There are many factors presently that hinder people with schizophrenia from being able to make that choice. In the following chapter we discuss some of the barriers to employment identified for people with schizophrenia in Germany.

## Chapter 3 Barriers to employment for people with schizophrenia

Despite the evidence that as many as half of people with schizophrenia have the capacity, capability and the desire to work (Marwaha & Johnson, 2004) employment rates remain disappointingly low. People with severe mental health conditions, and particularly schizophrenia, experience numerous barriers to finding employment – stretching beyond the nature of the illness itself (Gioia, 2005; Marwaha & Johnson, 2004; World Health Organization, 2001).

Along with the effect of symptoms and medication, the stigma associated with mental health conditions, and particularly schizophrenia, has been identified as influencing employment prospects. This is not only identified in individuals attitudes, but some suggest that stigma is inbuilt into Germany's systems and structures (Schulze & Angermeyer, 2003). Barriers are also found in the nature of the labour market, and in terms of other social and economic pressures faced by individuals. Previous research has also suggested that demographic factors might influence employment for people with schizophrenia – in Germany employment outcomes have been associated with area of residence, age, and having been born in another country (Marwaha et al., 2007).

Reviewing the existing evidence and the evidence gathered in this study and in the UK study (Bevan et al., 2013), barriers have been grouped into three categories: Individual health; attitudes, and the nature of the labour market.

### 3.1 Individual health

Individual factors (as they are termed here) are those that present in an individual with schizophrenia and are seen intrinsically as part of having the condition, but which will may be experienced differently by different individuals with the condition. The influence of symptoms, types and severity, including insight into the condition are key considerations, as are the extent of an individual's motivation to work and an individual's physical health – both of which are influenced by the condition and by treatment, as well as other social determinants.

[Interviewer:] *What, do you think, are the most important factors influencing your ability to stay in work?*

[Participant:] *Well, that I remain more or less healthy.*

— Lived Experience

#### 3.1.1 Symptoms & relapse

Severity of symptoms, both positive and negative, the number of psychotic episodes an individual experiences, and their level of insight into their condition have been associated with poorer employment outcomes (Erickson, Jaafari, & Lysaker, 2011; Marwaha et al.,

2007). The fluctuating nature of symptoms and the incidence of relapse are important considerations for work retention.

*If someone really suffers from enduring strong hallucinations or has strong delusions and is so distracted by this that they cannot connect to this fleeting actuality of life that we experience, then working is equally as difficult as social contacts or any other things.*

— Rehabilitation Specialist

Though emphasis is often placed on the role of positive symptoms, improvements in treatment and increasing attention to early intervention have meant that the experience of positive symptoms is less common. Research also suggests that in many cases, continuing positive symptoms may not actually be in themselves a barrier to working (Bevan et al., 2013; Erickson et al., 2011).

*And then of course, with a certain percentage of people with severe mental illness, they are likely to be getting on very well in the first line labour market. And they may hallucinate but they may be getting on well for ten years or twenty or thirty in some ordinary job because having symptoms of a severe mental illness doesn't preclude people getting their work done.*

— Psychiatrist/Academic

This was reflected in lived experience interviews, where there was little reference to positive symptoms affecting work, with the general view that these were being well controlled by medication. Much more common was discussion of aspects of the illness which might be seen as negative symptoms, in particular poor resilience to stress and lethargy, as well as issues with cognition.

The role of medication in managing negative and cognitive symptoms is less clear (Buckley & Stahl, 2007; Erhart, Marder, & Carpenter, 2006; Leucht et al., 2009; Lieberman et al., 2005; Stargardt, Weinbrenner, Busse, Juckel, & Gericke, 2008). Negative and cognitive symptoms have a considerable effect on an individual's ability to work, with greater severity of negative symptoms and greater cognitive impairment both having been associated with worse vocational outcomes (Bevan et al., 2013; Drake et al., 2013; Erickson et al., 2011; Evans et al., 2004; McGurk & Mueser, 2004; Mueser et al., 2001). Negative symptoms are also seen as having a relationship with work performance (Erickson et al., 2011).

The importance of negative symptoms, and their recurrence as regards work was also reflected in expert interviews.

*One factor is certainly how strongly pronounced the negative symptoms of the schizophrenia are. If there are very strong negative symptoms, it will be hard to go back to work.*

— Psychiatrist

One carer described how negative and cognitive symptoms were preventing her brother from working.

*Well, he can't remember anything and he's always somehow living in a different world and he has no self-motivation. So, when he's supposed to do a job, then he doesn't know where to start and how to proceed. Every single step has to be spelled out for him. We're so glad that he gets his pension.*

— Carer

Again reflecting previous evidence, an individual's level of social functioning was identified as having a role in employment (Mueser et al., 2001). Participants noted the importance of having the ability to interact with colleagues and employers and knowing appropriate social behaviours.

*The one thing that isn't mentioned here though and what has an even bigger impact on the symptoms, what has a bigger impact than symptoms or work environment or attitude, is social competence... ..even if the symptoms are very strong, if that person deals with the symptoms and still manages to interact with others appropriately, then they can be integrated.*

— Occupational Therapist

*Well I have problems connecting with people and also keeping contacts going. I also have the slight feeling of being excluded. Because of that I'm also quite shy and quite insecure, insecure in myself.*

— Lived Experience

Among the cohort of mainly employed lived experience participants, relationships with colleagues were generally seen as good, inferring that social skills were not a primary concern for this small group. Employer participants also did not note this as a concern, though this, of course, might be different in the open labour market (with employer participants working in the supported employment sector).

Vulnerability to stress and poor stress resilience were highlighted by expert and lived experience participants as a feature of schizophrenia they felt presented a barrier to working. Such findings have been identified in earlier studies (Norman & Malla, 1993).

*Our patients are not stress resilient, that is part of the illness. That is, there is a diminished protective ability towards the outside world, which is also partly a cause of the illness.*

— Rehabilitation Specialist

Both lived experience and many expert participants considered stress as an important aspect in employment decisions.

*if you are looking at work on the mainstream labour market, with jobs like yours or mine... then one of the hurdles would be the ability to work under pressure, because we all know that now and again there'll be a lot on at work and then these things just have to get done, you know that, I know that, we all know that.*

— BMAS Civil Servant

*I think, if I had to concentrate for hours at a time or had to deal with clients a lot, that would be very stressful and then I would definitely get ill again, so that mustn't happen at the moment, but I feel well enough for a part-time job, if it doesn't involve any time pressure*  
— Lived Experience

An individual's insight into their condition (such as poor resilience to stress) might allow them to identify ways to manage their health at work, and remain in work. One participant highlighted that stress management had been a valuable feature of their vocational training.

*I already had to learn during my vocational training to manage stress. I had to work on my stress-resilience, which had to be improved and that's when I reached my limits. But now I know exactly how to deal with that, how to react, e.g. to take myself out of it, listening to music or reading.*  
— Lived Experience

Previous research has also indicated a relationship between condition insight and work performance (Erickson et al., 2011), implying that an individual's awareness of their health and ability to reflect on what causes ill-health for them, is also a possible barrier or enabler for work. A number of participants talked about their awareness of their health, and the symptoms and changes which might mean that their health is changing.

*When I get a psychotic episode I get what's called delusion of reference, that's these stimuli that trigger that I receive messages. I start being very nervous and that's the early signs that I'm getting really ill and that I need to go to a hospital or have my medication adjusted.*  
— Lived Experience

Some participants also noted the role of colleagues in identifying early signs and assisting their self-management.

The experience of relapse can have a considerable affect on job retention, often resulting in a long period of sickness absence or a period of hospitalisation. Frequent in-patient stays are seen as endangering occupational (and social) integration (Zeidler et al., 2012).

One participant spoke about the experience of relapse harming their ability to recover, and how they felt this influenced their ability to work in the longer term.

*At that time I was much more able to work than I am now, because I've had at least four psychotic episodes in the meantime... and with me, I take longer and longer with each psychosis to get back to full capacity and I now have the feeling that I'm not reaching full capacity at all anymore.*  
— Lived Experience

An important finding from this study is that the experience of relapse was not seen necessarily as a barrier to returning to work – with most lived experience participants having experienced relapse and returned to work after a short period of sickness absence.

### 3.1.2 Motivation

An individual's motivation to work is an important predictor of employment for people with severe mental illness (Cook et al., 2008; Drake, Becker, Clark, & Mueser, 1999; Rosenheck et al., 2006). Prior research has indicated that 60-70 per cent of people with severe mental illness might be interested in working (Macias, DeCarlo, Wang, Frey, & Barreira, 2001; Mueser et al., 2001).

*My determination, that's how I see it. My determination. Yes, I want to do it.*

— Lived Experience

*I can't work like other people, I do know that, but I have some qualities that I can pass on and I'll have to see how it goes.*

— Lived Experience

Some people with schizophrenia experience low motivation, sometimes attributed to negative symptoms of the condition, or to the side effects of medication (discussed in section 4.1), though often this will be compounded by external factors, including knock backs during the job search, and in reaction to the experience of stigma and discrimination). This is particularly so where the experience of stigma develops into the 'why-try' effect – a manifestation of self-stigma that reduces motivation for pursuing opportunities and achieving life goals, including decisions to access vocational support services and resources (Corrigan, Larson, & Rüsche, 2009). The role that others attitudes can play on self-belief and motivation to work is discussed in section 3.2 below.

It was suggested in interviews that reflecting on how the condition has affected an individual, particularly in terms of cognition or prior educational or work prospects, might be a driver of low motivation – with lost opportunities, or in some cases lost abilities, resulting in disappointment for the individual which might make maintaining motivation much more difficult.

*When he was younger, he always compared himself with before. He was really good at university. He's mulled this over again and again in his head, it really brought him down.*

— Carer

Participants in our study were highly motivated to work, all actively seeking employment, or working in roles they purported to enjoy.

[Interviewer:] *Where would you like to see yourself in five years time?*

[Participant:] *Where I am today.*

— Lived Experience

*I'm completely happy with my position at the moment.*

— Lived Experience

Confidence was raised a few times as a factor – for example, in terms of its influence on an

individual's ability to make the transition from Occupational Therapy or other vocational support into employment. In some cases, lived experience participants reported having been reticent about starting a job long-term, fearing they were not ready, but then spoke about how they were supported through these concerns.

*Ok, so first of all I got an internship with [company] fixed term for six months, and I think they were prepared to employ me permanently after about 2-3 months, so pay me permanently, but I was a bit cautious and said, let's see if it works out for six months, if I can prove myself. And that was the case and then I got a two-year contract first of all and then that was turned into a permanent contract even before the two years were up.*

— Lived Experience

Being employed has also been associated with increasing an individual's motivation (Bryson et al., 2002).

### **3.1.3 Other health barriers**

Many health conditions have an influence on employment outcomes. Co-occurring health conditions, physical and mental can present further barriers to employment for people with schizophrenia (Bevan et al., 2013). People with schizophrenia in Germany are more likely to smoke, be overweight/obese, and have hypertension, and are also more likely to be addicted to illicit drugs than the general population (Drake et al., 2013; Marwaha et al., 2007; Papageorgiou et al., 2011), thus making them more likely to have poorer physical health. This is compounded by the findings that health professionals are less likely to consider the physical health needs of someone with schizophrenia than they do the general population, thus reducing access to treatment and support (Royal College of Psychiatrists, 2012; Schulze & Angermeyer, 2003).

Comorbid mental health conditions, depression and particularly anxiety were mentioned by some lived experience participants, the symptoms of which were found to be a further difficulty in work retention and in terms of sickness absence.

*Then last year I had twice, but they were not psychotic episodes, but, how shall I put it, anxiety attacks, anxiety.*

— Lived Experience

## **3.2 Attitudes towards schizophrenia: Stigma and discrimination**

Sometimes referred to as a "second illness" (Finzen, 1996), the stigma attached to schizophrenia is considerable – be it in the form of ignorance, prejudice, or discriminatory behaviour (Thornicroft, 2006). This is particularly apparent in respect to employment (Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009), with a considerable proportion of individuals with schizophrenia reporting moderate or high perceived discrimination when applying for work, training or education (Brohan, Elgie, Sartorius, & Thornicroft, 2010). It has been identified as the most prominent non-clinical reason for low employment among people with schizophrenia (Schulze & Angermeyer, 2003; Thornicroft et al., 2009).



*I am very stable and I know what this illness means and that's different from what society interprets it as.*

— Lived Experience

Research from Germany identifies positive changes in stigmatised attitudes towards people with mental health conditions, but highlights that there is still a long way to go in terms of social acceptance (Angermeyer & Matschinger, 2005; McDaid, 2010; The Economist Intelligence Unit, 2014). This goes beyond individual attitudes, with some commentators suggesting that stigmatised attitudes can be found in throughout German systems – in legal regulations, health insurance statutes and political decisions (Schulze & Angermeyer, 2003).

Research in Germany over the past 20 years has also indicated a public perception of people with schizophrenia as being unpredictable, aggressive, dangerous, unreasonable, unintelligent (and highly intelligent), lacking in self-control and frightening, as well as being highly intelligent (Angermeyer & Matschinger, 1995a; Gaebel, Baumann, Witte, & Zäske, 2002). Many people are reluctant to socially engage with people with schizophrenia, for example to share a flat, recommend someone for a job, or look after their children (Angermeyer & Matschinger, 1995b). Media portrayal of schizophrenia is often suggested as having some responsibility for this (Benbow, 2007; Bevan et al., 2013).

*The term schizophrenia causes fear amongst the general public and with employers, who don't know anything about it. Why does it scare people? If you turn on the telly or any other media then the portrayal of the term schizophrenia or people with mental illnesses is not particularly favourable for these people and that's why people are insecure.*

— Employer, Social Firm

Many people are aware that the media provides an unfair representation, and would like to learn more about and address their ignorance about mental illness (Gaebel et al., 2002). Despite evidence of the public's negative associations of the term 'schizophrenia', many people do not actually have a clear understanding of the condition or its symptoms, and do not understand that recovery is possible (Olafsdottir & Pescosolido, 2011). However, attempts at public education programmes and population interventions aimed at reducing stigma, raising awareness, and increasing mental health literacy have historically been found to have limited effect in changing public perception (Angermeyer, Holzinger, & Matschinger, 2009; Gaebel et al., 2008; Phelan & Link, 1998; Phelan, Link, Stueve, & Pescosolido, 2000).

In regards to employment, a survey of the German public found half of participants thought that someone with schizophrenia was able to work in a 'regular' job. Responses from younger participants were more positive, implying that this figure may have since risen (Gaebel et al., 2002).

*I guess that the increasing number of lost jobs or the lack of chances to get into a job over the last 20 years or so among the people with schizophrenia are also caused by the decreasing tolerance and increasing stress in our modern working society.*

— Employment Specialist

Attitudes within the general population will likely be reflective of attitudes of employers and employee more broadly (i.e. potential co-workers), who will have a direct role in providing employment and in job retention. Others attitudes may also have an indirect effect on an individual's ability to find and maintain work. Stigmatised attitudes toward schizophrenia and what the diagnosis means may influence an individual's self-belief (Corrigan & Watson, 2002). An individual's awareness of the stereotype, agreement with it, and applying it to one's self, culminates in what is known as 'self-stigma', often with the consequence of reduced self-esteem and self-efficacy (Corrigan et al., 2009). Self-stigma is common (Brohan, Elgie, et al., 2010), and has been identified as having a considerable affect on an individual's confidence and motivation to work – causing them to doubt themselves and their abilities in line with others' beliefs, culminating in a defeated 'why-try?' attitude (Corrigan et al., 2009).

*Somehow you just get a bit lost then. You start thinking, you're already a wreck now. You put yourself down. But let's face it, society does that too.*

— Lived Experience

There are many people who might influence whether an individual believes they have the capacity and capability to work, and whether they should be seeking work. Along with employers and co-workers, the following section considers the influence of health and rehabilitation professionals and families/carers, as well as looking at where systems and structures may be providing barriers.

### **3.2.1 Health and rehabilitation professionals**

Health professionals (HPs) are no less susceptible to stigmatizing beliefs than the general population (Ping Tsao, Tummala, & Roberts, 2008). Though work has not been found to have an adverse impact on health (including symptoms and hospitalisations), and may in fact have benefits in terms of health and well-being (Burns et al., 2009), research has also shown that HPs concerns about work having negative implications for their patient's health can negatively influence that individuals' employment prospects (Burns et al., 2009; Marwaha, Balachandra, & Johnson, 2009; Riedel, Lindenbach, Kilian, & Angermeyer, 1998).

Patients with schizophrenia have reported being discouraged from education and employment aspirations by negative views from HPs – feeling 'written off' by negative prognosis, or being told their condition was severely life-limiting and that there was little hope for their recovery (Schulze & Angermeyer, 2003). It understandably follows that if those who manage your healthcare are not positive about employment, then this may affect your inclination to seek or remain in work.

Participants from the health and vocational rehabilitation sectors were generally positive about employment and felt it was important. The extent of this varied between professionals, with more positive attitudes found among those in rehabilitation and less positive in medical treatment roles.

*With illnesses like depression or other anxiety disorders or with compulsive disorders I would*

*say yes, being able to work should be a goal to work towards. With schizophrenia, I doubt that this is possible.*

— Psychiatrist

*Gosh, you know, I'd say, we don't really care that much about the diagnosis as such. I've had the experience that unfortunately if certain therapists read a certain diagnosis they immediately flip this switch and all they see is this diagnosis.*

— Employer, Social Firm

HPs have been found to show greater reticence about work when it comes to their own patients (Marwaha et al., 2009), about whom they will have considerable knowledge, and heightened concern. The onus might be more likely to be on symptomatic recovery rather than broader social recovery and integration. In the UK, a low appreciation among some HPs of the importance of work as a health outcome has been identified as a barrier to employment (Bevan et al., 2013; Marwaha et al., 2009). Similar concerns were identified in Germany though there was a feeling among many that progress in this area had been made.

*I've worked in this area and in this service for ten years and there has been a very slight increase in the focus on work as an outcome, as an issue, but I think this is in no way sufficient.*

— Psychiatrist/Academic

Though not all clinician participants referred to work as a health outcome, it was clearly seen as a stabilising factor by expert participants.

*On the whole, I think the message has got through to the clinical teams by now that work is a very important factor for stabilising the clients.*

— Employment Specialist

The influence of HPs on employment was under recognised by participants, likely influenced by the segregation of medical and vocational systems in Germany. Family doctors (GPs or *Hausarzt*) in particular were seen as having little role in relation to employment, with stakeholders suggesting they were of little relevance to this study. However, previous research has identified HPs, including family doctors, often have an influential role (Bevan et al., 2013). As the study continued however it became clear that HPs had considerable influence in terms of providing ongoing support for individuals to remain at work, and particularly at the start of internships or work placements, where new pressures may have an effect on symptoms or wellbeing.

Participants with lived experience of schizophrenia spoke positively about HPs, with several noting their doctor having asked them about their desire to continue working, and in some cases even engaging with the employer to support that. Whether this is only true of those already in work seeking to retain work, rather than those seeking a new job was not clear.

### 3.2.2 Families and carers

As part of an individual personal support network, families and carers may also have an influencing role in terms of an individual's motivation and self-belief about ability to work. Lived experience participants spoke a great deal about the role their families had in their care, and in particular linking them in with various health and support services.

*Thank God I had the idea to get in touch with my parents, they took me to see a psychiatrist and he admitted me to hospital. Otherwise I wouldn't have got into this, let's say, support system at all.*

— Lived Experience

A number of lived experience participants noted family linking them into job opportunities, using their own contacts and making personal recommendations to assist them to find work. Experts we interviewed generally viewed carers/family members as having a positive influence on employment, though an example was presented of some families being unsupportive, fearing a loss of welfare payments, while others may not understand the nature of the condition.

*For example, if the family say, you don't need the medication, you are not ill, or something like that – that does happen, that the family has a different view, that they say, he's just lazy, we just have to put some pressure on – so if there are differences of opinion, then the situation gets tricky, indeed.*

— Occupational Therapist

One carer/family member described part of their role as protecting the person they cared for from the disappointment that might come from job seeking, particularly where realising that they would not be able to continue with the employment they had hoped for before the onset of their condition. Managing expectations was described as an important role for a carer/family member.

*I think you have to know the person very well and be able to talk to them, but if the ambitions of the person with the illness are too high, like with [name], he really thought he could continue his university degree and then he didn't make it, that's when you have to step in and help make them understand that that's not possible.*

— Carer

Though during interviews there was some suggestion that low confidence from a carer/family member might have influenced an individual's self-belief, conversely we found carer/family members as a source of motivation towards seeking or retaining employment. The same participant also described the importance of carers/family encouraging and supporting individuals.

*If someone just has no confidence at all even though they might be able to do something, then you have to encourage them, because, you know, how the affected person sees themselves and their situation is often not really very realistic either.*

— Carer

Such is the strength of potential influence that the attitudes of carers/families and HPs have, that in interviews it was suggested that this might lead to conflict for the individual with schizophrenia should these two influencers have differing attitudes.

*The important thing here is that the person doesn't receive opposing messages from them [carers] or the group of friends on the one hand and the professional rehabilitation team on the other.*

— Occupational Therapist

### **3.2.3 Employment and employers**

Employer attitudes will directly influence a person's ability to work. As well as making the hiring and retention decisions, they will likely also influence the way an individual thinks about themselves and their ability to work and to retain employment.

*The attitude of the employer is very important and I find that a very central point.*

— Rehabilitation Specialist

Germany like many other Western countries has taken a more open and proactive approach to the issue of mental health and work in recent years, identified as a key area of work for BMAS<sup>9</sup>. However, it has been suggested that employers have been slow to understand the challenges mental ill health poses (The Economist Intelligence Unit, 2014). A condition such as schizophrenia appears to be less well recognised as a work issue, with research suggesting that it is rarely considered as a workplace mental health condition (Little, Henderson, Brohan, & Thornicroft, 2011), with depression and 'burn-out' most common in Germany (Wilken & Breucker, 2000).

*He [manager] also told me that he'd had depressed phases, because that's socially quite acceptable.*

— Lived Experience

Stigma about schizophrenia is also identified in the workplace. This study adds to the weight of evidence that people with schizophrenia both experience and perceive negative discrimination in work (Schulze & Angermeyer, 2003; Thornicroft et al., 2009).

*So many times in my life I've been told that I'm no good for anything, that I'm too slow – a lot of the time probably also because I tried to do jobs that weren't the right thing for me, but apart from that, I've been told that a lot when I was really ill, that people said, how can you be so stupid, so slow, you should actually pay us to be allowed to work.*

— Lived Experience

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<sup>9</sup> <https://www.healthy-workplaces.eu/en/campaign-partners/national-focal-points/germany>

Many employers are reluctant to employ people with severe mental health conditions and disabilities (Olshansky, Grob, & Malamud, 1958; Waldschmidt, Lingnau, & Meinert, 2009), for example, many feel uncomfortable employing someone taking antipsychotic medicine (Scheid, 2005). Such employer attitudes are well-known – with a particular reluctance to employ someone with a previous mental health related hospitalisation (Gaebel et al., 2002; Scheid, 2005). This is reflected by individuals, with a considerable perception among people with schizophrenia that they are the most likely to be dismissed from their job (Schulze & Angermeyer, 2003). An attitude reflected among experts without lived experience as well. A health insurer has commented that for many employees, disclosing a mental health condition would be seen as a risky strategy, placing them at high risk of being “*the next ‘victim’ of a reorganisation*” (The Economist Intelligence Unit, 2014).

*If you take a company that is, let's say, completely inexperienced and don't know what this illness really means and what it is about, you'll find a lot of prejudice still.*

— Employer, Social Firm

Attitudes of co-workers, whether overtly discriminatory or just through being unsupportive, may also affect employment prospects (Nithsdale, Davies, & Croucher, 2008). Many individuals with severe mental illness have reported changes in colleagues' attitudes towards them upon returning to work after a period of ill-health – for example, making critical or negative remarks and denying previously proven skills (Schulze & Angermeyer, 2003; Stuart, 2006). One survey found 16 per cent of people would be ‘disturbed’ about working on the same job with someone with schizophrenia (Gaebel et al., 2002).

*I think that they [colleagues] convey something like if you spend time with them then schizophrenia is catching. In a way that's of course hilarious.*

— Lived Experience

The experience of stigma and discrimination at work, common for people with schizophrenia, can make decisions around whether to disclose the condition at work complex. In this study, (as in others) individuals were concerned about the reaction of employers and colleagues to their condition.

*Well, the most difficult part would definitely be to tell the boss about my diagnosis. That could be a problem, because there exists enough prejudice about that, not least because of films and so on, where schizophrenia is concerned, that these people are all violent and unpredictable.*

— Lived Experience

Some participants with lived experience sought to hide the specific nature of their condition from employers, while one participant sought to hide their disability status (*Schwerbehindertenausweis*)<sup>10</sup> entirely.

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<sup>10</sup> Individuals with disability assessed as being disabled to a degree of 50% or higher can be registered as severely disabled and receive a pass. This is discussed further in Chapter 4.

*Well, they all know, or my colleagues know that I'm severely disabled and I've got 50% degree of disability because of the mental health and so the closest colleagues are in the know, anyway.*

— Lived Experience

*It's a part-time job anyway, but that was what it was advertised as from the outset and no, because he [employer] doesn't even know, he doesn't even know that I've got a disability pass.*

— Lived Experience

The decision to disclose must be an individual one. Participants with lived experience of schizophrenia varied in their views on the merits and drawbacks of disclosure at work – while some actively advocated for disclosure, others went to lengths to avoid disclosure or simply saw no point in doing so.

*I said straight out that I have this illness, schizophrenia, and they stand by me.... if you apply for jobs, please talk about your illness. If you hide you create so much pressure for yourself and so much lack of understanding.*

— Lived Experience

*You shouldn't bear your soul to everyone, if you have a psychiatric condition, that you should talk about it too much at work, because that really has nothing to do with work, because the main thing at work is that you are able to do your work well, or if you can't manage to do your work anymore, be it because of a back injury, a psychiatric illness or because you become blind or anything else, then you just don't have a job anymore and that's just the way it is and my boss couldn't really help me with that anyway.*

— Lived Experience

Disclosure decisions are made after balancing the positive implications (e.g. support and open communication), which the possible negative consequences (e.g. stigma and discrimination). For some this decision was an ongoing deliberation.

*Yes, well, I have been thinking whether I should do that, but I think, well, my condition doesn't really affect my work. I mean, nobody would suspect that I've got this history and I think if I told them about it now, that would probably have disadvantages for me. Well, I could, I can imagine that at least some of them would have prejudices.*

— Lived Experience

Within these interviews, in several cases it seemed people had disclosed as they felt there was little choice. Some participants for example felt that they had to disclose, fearing that their poor health, sickness absence or health related behaviours might be perceived negatively by colleagues and employers or affect their ability to perform their job, placing their job at risk regardless. An example of this is a perception among employers of laziness, which in fact is caused by negative symptoms or medication side-effects (Lee, Chiu, Tsang, Chui, & Kleinman, 2006).



*You get a certain reaction if you are off work for a longer time. Or otherwise all sorts of rumours will appear if you don't say anything and in the end I found that quite difficult, too.*

— Lived Experience

*In the long run nothing would have been gained from keeping it a secret .... and you yourself don't really fancy putting up a pretence all the time and that people don't think that you just can't be bothered.*

— Lived Experience

*I had an experience... when I was released from hospital and a friend advised me "don't say that you have this illness". And what did I do? I lied. But it came out anyway, and that was worse than if I had told them, so I thought, no, I'll always tell them about my illness.*

— Lived Experience

*Colleagues and my boss were great, once they knew what was going on.*

— Lived Experience

One participant reported that even where their health became an issue at work, they would avoid naming their specific condition.

*Well, then I would say that I had been in [supported employment organisation] that I had had a mental-health problem or something like that but I wouldn't go into details.*

— Lived Experience

Employees with mental health conditions may report other, less stigmatised, health conditions (often physical conditions) to excuse sickness absence, rather than providing the real reason (Brohan et al., 2012; Schulze & Angermeyer, 2003). One participant described how they reported physical health conditions (in this case, a slipped disc and a metabolic disorder) to test the water, before feeling confident enough to raise their actual health condition. More often in our research, was the suggestion that a less stigmatised, more 'acceptable' mental health condition, namely depression, might be used to avoid full disclosure.

*Well, yes, employers could be more sensitised, but that is very difficult where schizophrenia is concerned, because here we are up against very negative and sensationalist media coverage of exceptional cases. In that case it is more helpful to call it depression, because everybody knows that and everybody knows someone who suffers from depression and so on.*

— Employment Specialist

*My boss doesn't know that I've been ill, but he did ask at some point, well I say he doesn't know, he asked, whether I had suffered from depression, because I was unemployed for two years, so I said yes, I had been depressed, because I was so down about becoming unemployed and he just swallowed that.*

— Lived Experience



One participant felt disclosure was important to explain their sometimes erratic behaviour to colleagues, to improve their understanding.

*[I disclosed] so that my colleagues might understand a bit better, when I'm a bit hyper, when I've had a bad night or haven't had any sleep at all. So that they understand better, why I'm sometimes tired because of the medication. So they understand better why I'm sometimes a bit crazy to put it bluntly.*

— Lived Experience

In this sense disclosure can be seen as having positive implications in terms of improving relationships with colleagues. The attitudes of and relationships with colleagues were highlighted by several participants as being very important to being able to return to work successfully.

*Sometimes my colleagues help me, too. That's great and that's something I would have wished I'd had after the last stay in hospital.*

— Lived Experience

Several participants discussed the value of good, open relationships with colleagues – not only in terms of friendship and support, but also as a trusted source of constructive feedback on work, or by being well-placed to notify an individual if their behaviours change (and thus aiding self-management).

*I'm always telling myself, if I'm not sustainable anymore, then they would tell me.*

— Lived Experience

Experience of lived experience participants of colleague supportiveness varied – with some reporting excellent relationships, while others seemed more wary.

*Relationships with colleagues? Excellent! Well, the first impression is reservation, but once they realise what you're about then there's acceptance, because, you see, we're a small company, about 28 people at the moment and... they come over quite often and ask "How are you today?" or "What have you done today?" or, if I'm feeling bad "Can I help you in any way?", it's not like they say "Keep away from me!", not at all, none of them.*

— Lived Experience

*Well, people greet me, they are friendly and it is good for me to be in touch with people, but I don't really have any deeper relationships with my colleagues.*

— Lived Experience

Advocates of disclosure suggested that it might have a role in addressing stigma – raising awareness and educating colleagues about the condition.

*If we hide then nobody will understand us. But, in my experience, if we are open about it and open up about it then have the chance to take away that stigma that we have.*

— Lived Experience

Indeed, having social or personal contact with someone with a mental health condition (including schizophrenia), has been shown to assist with the breaking down of negative stereotypes around mental illness (Angermeyer, Holzinger, & Matschinger, 2010; Angermeyer & Matschinger, 1997; Brohan, Henderson, Little, & Thornicroft, 2010; Couture & Penn, 2003).

*So you would need to have a boss, who is either already quite informed about the illness, or who is willing to get information about it. That's of course quite difficult. My boss, my former boss knew about it, because her sister-in-law was affected by the same condition, but most people do flinch when you mention the word "schizoid".*

— Lived Experience

Results around this were less clear where contact was work-based (Brohan, Henderson, et al., 2010; Hand & Tryssenaar, 2006), and experience of hiring someone with a mental health condition has been associated with increased wariness about the impact of symptoms (Brohan, Henderson, et al., 2010), suggesting that experience of employing alone does not necessarily increase employer confidence. Experts discussed the need for more support for employers to assist with job retention for people with schizophrenia.

*If you want to be successful in placing a schizophrenic person in the labour market, especially in the mainstream labour market, you have to invest a lot of time and effort into supporting the employers, because there is a lot of ignorance and also fear and our experience shows that the more you support the employer, the more secure the job is for the patient.*

— Rehabilitation Specialist

*I really think that the biggest problem is simply the fear of being confronted with something that you cannot handle.*

— Employer, Social Firm

Most lived experience participants reported having had sick leave related to their condition, the amount of absence varied considerably between participants. For example, one participant reported having had two periods off sick in 15 years, while another reported having had three periods of absence in their career, lasting between 2-7 weeks each. In another case however, an individual feared their absence was becoming problematic.

*Unfortunately I am off work quite regularly; I obviously am concerned about job security. At the moment there are no problems with my employer, but I just know that my illness will keep coming back and that obviously doesn't give a very stable impression, if it comes back again and again.*

— Lived Experience

Addressing workplace stigma is an ongoing battle. There is some evidence that improving managers (and colleagues) mental health literacy, through training, guidance and education programmes may help to address workplace stigma (Corrigan & Watson, 2002; Little et al., 2011). Though this may not be sufficient to negate the emotional response and subconscious bias (Angermeyer et al., 2010; Hand & Tryssenaar, 2006; Tal, Moran, Rooth, & Bendick Jr, 2009). Employer concerns about the difficulty of managing someone with schizophrenia might be addressed by the *Integrationsfachdienst* or Integration Service (IFD), which provides in-work support for employees with mental health (and physical health) conditions and disabilities to support their job retention. The extent to which this is available to and used by employers in Germany to support people with schizophrenia is unclear, though the proportion of users with mental conditions is thought to have reduced in recent years (Aktion Psychisch Kranke, 2007). This is discussed further in Chapter 4 and in Appendix 3.

Experts emphasise the importance of having a positive work environment to support an individual's wellbeing at work – with those employers who do not create a suitably supportive environment, not necessarily being suitable employers.

*You either have to have a nice surrounding to cope with your symptoms, or you do have more or less problems with your superiors, clientele, colleagues etc.*

— Employment Specialist

*I always say that an employer who is not sympathetic to people with mental illnesses is not a suitable employer – also not for myself.*

— Employment Specialist

### **3.2.4 Structures and systems**

It has been suggested that stigma and discrimination might also be experienced through imbalances and injustices inherent in social structures, political decisions and legal regulations (Schulze & Angermeyer, 2003). This includes the quality of the health and vocational rehabilitation systems, and how well they respond to the needs of people with schizophrenia. Chapter 4 discusses in depth how such services support employment.

Germany's legal and funding structures for service provision were frequently raised by experts interviews, as well as in the literature, as forming considerable barriers to accessing good quality, continuous vocational rehabilitation and employment support. The legal framework for social policy relating to people with disabilities or at risk of becoming disabled are all outlined in Book IX of the Social Code (*Sozialgesetzbuch – SGB*) (Bundesministerium für Arbeit und Soziales, 2014; Welti, 2002), with the relevant legal provisions falling in three sections – benefits for medical rehabilitation (ch. 4, § 26ff), vocational rehabilitation (ch. 5, § 33 ff) and social rehabilitation (ch. 7, § 55 et seq.). These benefits and provisions are funded via the five 'pillars' of German social security system: health insurance; long-term care insurance; pension insurance; unemployment insurance; and, work accident insurance (employer liability insurance). These are provided by multiple agencies, public and private, across different federal regions. Some insurances are further split, for example, insurance

through the National Employment Agency (*Bundesagentur für Arbeit*) has different governance arrangements for the short term workless and for longer term jobless who have made less social security contributions (falling under and Hartz IV or SGB II system).

Different services delivered at different stages of treatment and rehabilitation will be funded by different bodies. It has been suggested that insurers might try to 'shunt' people into another insurance category, thus reducing their liability. This means that some people may fall in the cracks between insurers, or that they may have a difficult time getting support from an insurer where their situation is complex. This structure also creates hurdles for people who need to move between services. For example, someone who is in a vocational rehabilitation service becomes ill and requires treatment; these two services are funded by different bodies meaning that when the individual recovers again, they will have to re-apply for the vocational rehabilitation service, which will involve reassessment and, depending on the service, often includes a considerable wait period. For someone with a severe mental health condition, this may affect motivation to work. It is also very onerous, and many people will be reliant on support (whether from supportive health professionals, social workers, *Betreuer*<sup>11</sup>, or carers) to help make the applications required to see if they are eligible for the service. Further to this, despite the Social Code giving a five week time frame for applications for insurance, in reality it is often much slower, and may take several months. This can have adverse implications for an applicant's health and wellbeing.

At this juncture, the relevant funding body will decide whether the applied for service is appropriate. One expert we spoke to suggested that schizophrenia is seen as relatively insecure from an insurance liability perspective. It is suggested therefore that attitudes to schizophrenia may influence insurer decisions, and therefore influence what services and support people with schizophrenia are able to access.

The complexity of the system, the work required to access it, and the ultimate reliance on the findings of an assessment by a funding body are all suggested to provide further barriers to employment, due to a lack of consideration of the particular needs of people with severe and fluctuating health conditions.

Welfare systems are also often seen as having inbuilt barriers for returning to employment. In particular, the possibility of a 'welfare trap' – where finding a job is seen as a risk and therefore a barrier to employment, as should the job not work out, the income previously received through welfare benefits might be jeopardised (European Commission, 2011). Recent cuts to welfare provision have been suggested as strengthening this barrier to employment. Germany, like many other countries, provide some welfare payments for people with severe disabilities who are in employment in part-time or low wage roles, and therefore require supplementary income. Recent cuts to welfare spending have been

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<sup>11</sup> The *'Betreuer'* (legal guardian) is responsible for looking after various social, medical and legal issues for their clients, to the end of protecting their welfare and helping them to continue to live independently and better integrate in society. *Betreuer* are usually assigned randomly to an individual (by the local court), though some have more specific types of carer duties (*Betreuerpflichten*), which might benefit different clients – e.g. a *Gesundheitsbetreuung* will focus on health, personal welfare, financial matters, housing, etc. Though the *Betreuer* will support and make recommendations, it is the court that decides which services an individual will receive, and this is assessed by the MDK.

accused of affecting individual's ability to work.

*We are faced with a number of cuts, there are a number of interventions, so called "Hartz IV" interventions<sup>12</sup>, where people could be employed in low-paying jobs... These measures where social benefits receivers can work in low-paying jobs, these have progressively been cut... This market should be opened up again for people who cannot work full time, who cannot take the pressures of a full time job, more opportunities for this kind of work should be created, but these have been cut more and more in the last two years, so that's difficult.*  
— Employment Specialist

### 3.3 The nature of the labour market

As discussed, the symptoms of the condition, particularly negative symptoms and the effect they have on motivation, as well as the attitudes of others, from health professionals to employers to those found within systems and structures, will all form barriers to employment. Taking an even wider view we must also consider the role of the broader labour market, the economy and culture around work in creating barriers to employment (Kilian & Becker, 2007), with macroeconomic factors such as national employment rates and social benefit expenditure being especially pertinent (Kilian & Becker, 2007; Warner, 2004).

The reality of the labour market, such as the number of jobs available, the nature of the jobs available, and the quality of the applicants, will all influence employment decisions (Marwaha & Johnson, 2004). Local unemployment rates have been found to influence job outcomes for people with mental health conditions, even when involved in employment support programmes (Burns et al., 2007). Where there is a low supply of jobs and high demand for them, employers may be more stringent about their criteria for selecting candidates. This may hinder an individual with schizophrenia's job prospects in several ways. One of these, as discussed above, is that stigmatised attitudes about people with schizophrenia and perceived work limitations may lead to the conception that they will not be productive as other possible job applicants.

*We have nowadays very high demands and expectations in the working world generally and there is very little room for people, who are "underachievers", whose performance is not one hundred percent.*  
— Rehabilitation Specialist

*We are bound by the rules of the market, and the market expects high quality and a high pace, or let's say, the combination of high quality and high pace. I regard this as quite unfavourable conditions for people with mental health problems. If I could change that and could change the conditions in here [the workplace], then I would very happily do that, I would be very open to that, but that's just not possible due to the constraints from the clients, from the outside.*  
— Employer, IFD

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<sup>12</sup> The social benefits reform of 2003 in which unemployment benefits and social welfare benefits were conflated into one system

Taking this a step further, the nature of available jobs may also be a factor – it has been suggested that a decline in lower skilled and lower demand roles may make finding any work harder for people who already struggle in the labour market (Nickell, 2004).

A change in culture, driven by globalisation and greater international economic pressure, was suggested by some participants as making the labour market less willing to take on, or tolerate, people who might be less productive.

*In the earlier years I couldn't do so much and that was accepted, but nowadays, that wouldn't work at all. That would have different consequences straight away, that you could lose your job. Back then it could be tolerated, it worked and through that I managed to create another sensible work area for me.*

— Lived Experience

A further factor of course is the how competitive the job market is at a given time – how many jobs are available. Level of education, qualifications, prior work experience, work history and work patterns will often influence whether someone gets a job. The same is true for those who have schizophrenia (Drake et al., 2013; Marwaha et al., 2007; Mueser et al., 2001). However, whether an employer knows that an individual has schizophrenia (or any health condition) it may be that gaps in employment or education seen on a job application on their own reduce chances of being given an interview or a job.

Many people with schizophrenia will have gaps in work history. This might occur, for example, due to job loss after an experience of discrimination, or a period of relapse resulting in time away from work. Others will not have had much work experience, if any – the age of onset of schizophrenia often means that people experience it during work training or at university, leaving them unable to complete, and severely jeopardising future prospects.

*I went back to university and when I had the first psychosis in [19]86, from then on I didn't do anything, really, dossing about.*

— Lived Experience

*When I did the Masters in business ... my grades were very good. I was one of the best. But I couldn't keep it up, because then I had that breakdown and after that we said, no, that's not going to work. I was too ill and I just couldn't manage it intellectually.*

— Lived Experience

Previous studies have highlighted the importance of qualifications as broadening choices for those seeking to re-enter the labour market (Marwaha et al., 2007), as well as a correlation between longer periods of education and higher rates of employment for people with schizophrenia (Greve & Nielsen, 2013; Marwaha et al., 2007). This study too emphasised the importance of completing further education for securing employment in the German labour market.

*Education, this is one thing, so if you manage to have a good education the chances are better. In all regions of the labour market, if you have uni education it might be easier.*

— Employment Specialist

Not all experts felt completion of education was sufficient for someone to break into the open labour market however.

*Most of the time those are very young people, usually in the middle of their job training and in those cases we do try to support them in a way that they can continue their apprenticeships and they can finish their training. There are also a lot of students and I know several who occasionally are re-admitted here, who have managed to finish their degrees. But then they failed on the open job market, nevertheless.*

— Social Worker

Prior experience of work has been identified as a stronger predictor of employment. Having worked recently (within the previous five years) has been found to be highly predictive of regaining employment. Research has identified that where someone with schizophrenia has had some work experience over the previous few years, then they the chances of finding work again are significantly increased, as is the speed of finding a job compared to someone who has not had recent work experience. (Catty et al., 2008).

*There are people who return to their job. But these are usually people who, in my observations, who had been in work regularly and for a long time before the illness.*

— Occupational Therapist

This presents particular issues for young people with schizophrenia, who, even if they have completed a course of education, may not have any work experience. Experts suggested that it was very difficult for young people with schizophrenia to get into the labour market in Germany.

*If you are young with severe mental illness then you don't get into the labour market in the first place.*

— Employment Specialist

The acute concern showed by some experts about the prospects of young people with schizophrenia today, particularly those who have not completed education and have no work experience, was reflected in lived experience interviews – in particular the youngest participant, who was diagnosed just before he was due to sit his final exams, and at the time of interview had been unable to find a paid job.

High unemployment and extensive cuts to funding for social policy seen across Europe as a result of the recent financial crisis, created a context of pessimism for some participants, who feared future employment prospects for people with schizophrenia would get worse should the current same path of macroeconomic policy continue.



*We live in times of ever greater financial cuts, where the pressure rises and rises, where the workload gets ever greater, and I am rather pessimistic – I think that the situation will worsen rather than get better.*

— Psychiatrist

### **3.4 Conclusion**

There is a range of clinical and social factors which are associated with the condition schizophrenia – these factors separately, and more so together, create significant barriers to employment for this group. Consequently, despite many people being able to work, being motivated to work, and having skills and knowledge which are valuable in the labour market, many are unable to find work in the open labour market. This is particularly concerning when considering that work has been demonstrated to have positive implications for health, and that many people with schizophrenia see achieving work as a signal of their recovery.

Clinical symptoms associated with the condition, particularly difficult to treat negative symptoms, create a significant barrier, as does the nature of the labour market, and the way people are treated within it. The attitudes of others towards people with schizophrenia, often based on stigmatised attitudes and misinformation also create a considerable barrier to employment – arguably a more modifiable barrier. Negative views of individual's ability to work are not just found among employers, but among those who have an important role in encouraging, or discouraging people from seeing work as something they might aspire to and reasonably achieve. Greater appreciation for the individual's skills, abilities, motivation and desire to work needs to be achieved, as does greater awareness of the important role work can give in terms of health and recovery.

It is not just about individuals – attitudes and barriers built into systems and structures are also problematic. This includes within the mental health system and particularly the way that mental health treatment and vocational rehabilitation are funded.

In the following chapter we look at how mental health treatment and vocational rehabilitation support employment for people with schizophrenia, as well as how they do not. Similarly we review elements of labour market policy for people with disabilities and health conditions, and how well this works for people with schizophrenia.



## Chapter 4 Supporting Employment – through treatment, rehabilitation, welfare and integration

The German health and rehabilitation systems are designed to not only aid clinical recovery, but also to support integration of individuals with health conditions and disabilities. The general goal of German law in regards to the provision of support for people with disabilities is to overcome the disability's effects as much as possible and to enable people with disabilities to participate in all areas of society, especially in the labour market and in community life (Kock, 2004). Indeed, integration, and particularly labour market integration, is afforded high status in German disability policy (Waldschmidt, 2009) – according to BMAS 'self-determined integration into society takes precedence over care and provision' (Bundesministerium für Arbeit und Soziales, 2014).

*Well, I believe that work is basic right, a basic participatory law of life. That would be like asking me if I would find it reasonable that people with schizophrenia should eat, drink, sleep or breathe.*

— Occupational Therapist

Moving beyond access to treatment, Germany has both an extensive vocational rehabilitation system, including sheltered work options and supported/work integration programmes, and a system of policies and interventions which encourage and support the employment of people with health conditions and disabilities.

There is widespread support for such services and policies, seen as moral imperative. However, the reality of economic difficulties in recent years have affected the provision of such measures – increased unemployment in the wider population has reduced job opportunities, while financial cuts in welfare services have increased pressure on support provision (Waldschmidt et al., 2009).

*In the end it is more of an ethical question – how much are we prepared to spend? And of course this is a question for the political decision makers; do they encourage a public debate on this? Do they speak out in favour of it? Or do they rather think: "Those are the weakest in society, they can't defend themselves, this is where we can cut even more money". So, essentially, the politicians would have to be advocates for the ill people and say, there might not be a profit in this, but we owe it to ourselves as a society that we take good care of our ill.*

— Rehabilitation Specialist

Support for employment can be seen in three parts: medical treatment and rehabilitation; disability employment activation policies; and, vocational rehabilitation/work integration services. In the following chapter we look at how these systems support the employment of people with schizophrenia.

## 4.1 Medical Treatment and Rehabilitation

Medical treatment and rehabilitation services for people with mental health conditions play a considerable role in supporting the clinical and functional aspects of recovery, through timely provision of appropriate services.

In this section we will briefly review the mental health system in Germany, before taking a more in depth look at early intervention and access to different treatments, and how they might affect employment outcomes.

### 4.1.1 Mental healthcare system

The German healthcare system is widely considered to be one of the best in the world (Schulz, 2012). A recent survey by The Economist on mental illness and integration found Germany scoring highest out of 30 European countries on access to health services, with the rehabilitation aspect is also highly regarded (The Economist Intelligence Unit, 2014).

*I have to say, in Germany we have such a fine-tuned, well developed rehabilitation system, you won't find that anywhere else in the world, only we have something like that.*

— Employment Specialist

Concerns remain however about how well the system supports people with more severe, and more highly stigmatised mental health conditions, such as schizophrenia.

*I think the conditions in the workplace as well as the health system are becoming worse for people with schizophrenia, they go under in this system rather than having better chances.*

— Psychiatrist

The mental healthcare system has historically been subject to criticism, accused of lacking insight into mental ill health and failing to screen for mental health conditions (Jacobi, Wittchen, & Holting, 2004). Mental health stigma has been described as the cause of underutilisation and poor quality of mental health services (Schulze & Angermeyer, 2003). Structural discrimination in the system may, as discussed above, exacerbate and be exacerbated by stigmatised attitudes among individual health professionals also. They will (or will not) encourage and support employment, link individuals into rehabilitation and support services, and importantly, make treatment decisions which directly influence people's ability to work.

The mental healthcare system in Germany, and the funding that supports it, is marked by its complexity and fragmentation (Bramsfeld, Wismar, & Mosebach, 2004; Kunze, Becker, & Priebe, 2004; Salize, Rössler, & Becker, 2007). Decentralized and multi-layered, responsibilities are shared between the federal authorities, the 16 states (*Länder*), local authorities, and semi-statutory organisations which govern out-patient healthcare provided by psychiatrists in office-based practices (Kunze et al., 2004).

Different aspects of medical treatment, medical/social rehabilitation and vocational

rehabilitation are separately distinguished in the social code<sup>13</sup> and funded in different ways, i.e. while acute medical treatment is funded through health insurance, 'aftercare', including medical, social and (to some extent) vocational rehabilitation, is funded by social security. Such distinction leads to the creation of artificial divides and silo-ing between services – for example, in-patient and out-patient care having separate funding and staffing (Salize et al., 2007). In terms of mental healthcare, considerable difficulties have been identified in getting the health and social insurance bodies to pay for services or to support inter-working between mental health and other health professionals (Kunze et al., 2004; Schulze & Angermeyer, 2003). Accessing mental health services is usually via prescription from a specialist physician, often a psychiatrist or neurologist. Referrals are reviewed by the health insurance provider (*Krankenkassen*), and approved by its medical services (*Medizinischer Dienst der Krankenkassen*). Health insurance may be public or privately provided.

In recent years Germany mental healthcare has seen a shift towards out-patient and community mental health service provision, including residential and day-care services (Salize et al., 2007). However, experts suggest that care provision remains tipped towards in-patient care. Rather than the development of community facilities and integrated psychiatric units replacing psychiatric hospitals as has been common in other countries in Western Europe, hospitals have been downsized with such services developed alongside them (Bauer, Kunze, Von Cranach, Fritze, & Becker, 2001). Community-based services are weak and fragmented, with no organisation having sole responsibility for services in a given catchment area (Kunze et al., 2004).

*It's a shame that normally patients get admitted to hospital stay as in-patients, instead of being day or out-patients or having crisis intervention in the family first. After shorter and shorter [hospital] stays, with luck patients get into day hospitals and well structured out-patient care, including family care and if needed hostel or group homes with long standing care by social workers etc.*

— Occupational Therapist

Out-patient care in Germany is dominated by office-based specialists – a situation which has been criticised for adding to the complexity of the health system by presenting further intricacies for patients to negotiate (Salize et al., 2007). Experts suggested that the office-based specialist model was a barrier to multi-disciplinary community care. Though some offices may have some support, i.e. from psychological, nursing, or social worker colleagues, such interaction with other professions is limited.

*We have this ailing system, or the system is in a crisis so we have this system of office based specialist healthcare.... so a patient may well be in touch with a psychiatrist in that type of office based practice, but usually no multidisciplinary team.*

— Occupational Therapist

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<sup>13</sup> The legal basis for the mental health system is outlined under § 37 of the social code.

The shift towards out-patient and community care provision was supported by expert participants, though some were concerned that reduced in-patient and residential provision were in some cases due to financial reasons rather than reflecting patient needs. One expert described the effect this was having on residential, rehabilitation services, suggesting there was a particular imperative to cut social security funded rehabilitation services.

*Here we've seen a pretty widespread eagerness to cut spending, because these are very high costs and there have been deep cuts here. These residential places that we offer, these live-in residential places are being systematically cut in favour of out-patient places, which is good sometimes, but often it offers too little support; so in this respect the political landscape for these socio-psychiatric things, for the aftercare, is diminishing, that's difficult .*

— Rehabilitation Specialist

This participant further suggested that cuts to in-patient services had in some cases led to 'drastic' reductions in the time allowed for treatment, resulted in people being moved into rehabilitation services before they are ready, increasing the likelihood of relapse.

*The treatment time is on average 27 days, which is much too short for seriously ill patients; and those patients just end up, like in a revolving door, being discharged too soon, relapsing and going back into hospital.*

— Rehabilitation Specialist

*It costs a lot of money and overall, there are a lot of cuts, there's cuts everywhere.*

— Employment Specialist

#### **4.1.2 Early intervention**

Research shows the first three years of psychosis represent a critical period in terms of recovery (Birchwood, Todd, & Jackson, 1998). Earlier treatment interventions, continuous access to comprehensive mental health services, and social support are associated with symptomatic and other recovery outcomes for people with schizophrenia (Alvarez-Jimenez et al., 2011; Hill et al., 2012; Liberman et al., 2002; Marshall & Rathbone, 2011). A longer duration of untreated psychosis (DUP) is related to poorer outcomes (Loebel et al., 1992), for example more severe positive and negative symptoms, lower chance of remission, poorer social outcomes and poorer functioning (Barnes et al., 2008; Boonstra et al., 2012; Chang et al., 2012; Hill et al., 2012; Marshall et al., 2005), while some studies also indicate an association with employment outcomes (Greve & Nielsen, 2013; Hill et al., 2012; Norman et al., 2007).

*I had trouble sleeping, crazy thoughts, which I didn't follow up, though. Because I obviously didn't think that I was crazy. Back then there was also no early diagnosis centre [Früherkennungszentrum]. Now there is one for psychosis here on the premises. I just thought I was overworked. I also kept on working as normal.*

— Lived Experience

Many countries have specific services targeted at early intervention for young people (e.g. the UK's Early Intervention Psychosis teams). In Germany, services for early diagnosis and intervention of psychotic illnesses are available through some psychiatric out-patients clinics, such as the Early Detection and Therapy Centre (FETZ) in Berlin<sup>14</sup>. There is no national provision however, and these tend to be limited to big cities.

*In the big cities we would have I think about 15 first episode services, we have no even coverage of first episode services as in the UK. But we do have first episode services in big hospitals in big psychiatry services. We have no dedicated, no specialist first episode service, no first episode clinic at this service at present, I hope that will change in the near future – you do find that in other places but you don't find it across the country.*

— Psychiatrist/Academic

The gaps in these services were discussed by another expert, who highlighted the process he had seen for young patients with schizophrenia in terms of early and consistent access to healthcare.

*Usually you just have a doctor.... and the doctor doesn't have really much time. If you're not a usual patient for that doctor, you might have to wait 3 or 4 months till you get an appointment with them. You can go to a clinic, they have ambulances and they can support you, but they don't have teams that come to your home... so you're kind of lost in the system. You might get into a clinic, a ward, 24 hour support. They have day care but not that much nor so often as is needed, and the day clinics are more aimed at people with less severe mental illness. Having schizophrenia at 18 I would guess you would get into a ward/clinic, stay for 2, 3, 4 weeks, get medication, and that's it.*

— Employment Specialist

The International First Episode Vocational Recovery Group (2010) has called for greater focus on functional recovery (alongside symptomatic recovery) in early intervention/first episode services. It is unclear from this study how much consideration is given to functional and employment-related outcomes in German provision for early intervention in psychosis.

### **4.1.3 Treatment and rehabilitation interventions**

The guidelines for the treatment of schizophrenia, developed by the German Association for Psychiatry, Psychotherapy and Neurology (DGPPN, 2006), set out the evidence-base for pharmacotherapy, psychotherapy, “help systems” and socio-therapy. In this study we consider these through the lens of employment outcomes.

Expert and lived experience interviews reflected the guidelines in identifying pharmacological treatment as the primary treatment for schizophrenia, with the use of medication strongly advocated in most cases. Both the DGPPN guidelines<sup>15</sup> and the interviews emphasised the importance of individuals having access to a range of treatment options.

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<sup>14</sup> Berlin-Brandenburg, Department of Psychiatry and Psychotherapy.

<sup>15</sup> According to the DGPPN-S3 guideline ‘Pharmacotherapy should be embedded in an overall treatment plan, including general and specific psychotherapy, therapeutic and socio- occupational therapy measures and psychiatric treatment care in response to a differential indication’

*Medication is important, psychotherapy is important, different things are important for different people..... The main thing is that there is as broad and differentiated a range of provisions as possible.*

— Occupational Therapist

In reality however, interviewees noted poorer access to non-pharmacological treatment, particularly socio-therapeutic interventions, reflecting findings from other studies suggesting that treatment for managing schizophrenia is disproportionately focussed on medication (Lepping, Sambhi, Whittington, Lane, & Poole, 2011; A. P. Morrison, Hutton, Wardle, et al., 2012; Schulze & Angermeyer, 2003).

#### **4.1.3.1 Pharmacological interventions: Antipsychotic medication**

Pharmacological intervention is usually seen as the first course of action in the treatment of the symptoms of schizophrenia and in the ongoing management of the condition.

*Pharmacotherapy, which is of course the indispensable basis [of treatment].*

— Rehabilitation Specialist

*I still have to take the medication, can't afford to forget that.*

— Lived Experience

Antipsychotic medication<sup>16</sup> works on neurotransmitters in the brain, and is associated with the reduction of positive symptoms such as hallucinations, delusions and thought disorders (DGPPN, 2006; Moncrieff, Cohen, & Mason, 2009; Velligan & Alphas, 2008). Maintenance of antipsychotic medication has also been associated with improvements in health-related quality of life, psychosocial and cognitive functioning and greater vocational success (Alonso et al., 2009; Corrigan, Reinke, Landsberger, Charate, & Toombs, 2003; Guo et al., 2011; Kim et al., 2009). This was reflected in interviews with lived experience participants and experts.

*I'm managing quite well at the moment with the way my medication is adjusted. I'm able to work and also be productive, I think, more or less.*

— Lived Experience

*If a patient's medication is adjusted well, so they do not suffer from any severe remaining symptoms, they can usually be re-integrated well into a job.*

— Employment Specialist

The role of antipsychotic medication in managing negative and cognitive symptoms is less clear (Buckley & Stahl, 2007; Erhart et al., 2006; Leucht et al., 2009; Lieberman et al., 2005; Stargardt et al., 2008). As discussed above, negative and cognitive symptoms have a considerable effect on an individual's ability to work, with greater severity of negative symptoms predicting worse vocational outcomes (Bevan et al., 2013; Erickson et al., 2011; Evans et al., 2004; McGurk & Mueser, 2004).

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<sup>16</sup> <http://www.rcpsych.ac.uk/mentalhealthinfo/treatments/antipsychoticmedication.aspx>

The majority of experts and lived experience participants described antipsychotic medication as an essential part of treatment for someone with schizophrenia. All participants with lived experience of schizophrenia had taken antipsychotic medication, though one participant was not taking it at the time of interview.

Antipsychotics may not be effective for all people with a diagnosis of schizophrenia (estimated in the UK to help 80 per cent of people<sup>17</sup>). There has been some criticism of the efficacy of antipsychotic medication, and it has been suggested that for some individuals, symptoms may be manageable without pharmaceutical intervention, i.e. for those with better internal resources, greater resilience, fewer psychotic symptoms, fewer relapses and having had greater periods of recovery (Lepping et al., 2011; A. P. Morrison, Hutton, Wardle, et al., 2012). How many people this may be appropriate for is not currently clear.

There is no clear evidence to suggest that any particular type of antipsychotic medication is linked to better employment outcomes or ability to learn and undertake job tasks (Kopelowicz, Liberman, Wallace, Aguirre, & Mintz, 2009; Resnick et al., 2008), reflecting the variation in schizophrenia related symptomology as well as the wide range of medication types and dosages available.

*One person might be more anxious and might need something more sedating, while someone else might be more lacking in drive and need something more activating, so having different medications for the different forms and courses of schizophrenia is very important for me.*

— Psychiatrist

Emphasis is often placed on the balance between symptom control, while providing as low a dosage as possible.

*Generally I would think that in terms of a long-term support there has to be a continued maintenance medication, which has to be well adjusted, how much is minimally necessary, so as little as possible, but most patients cannot do without any medication...*

— Rehabilitation Specialist

Decisions on the type and dosage should be made on the basis of an individual's reactions and accompanying side effects (Leucht et al., 2009), as well with consideration of the individual's preferences (DGPPN, 2006) and recovery goals. Though the extent to which patient preference is accounted for has been questioned in previous studies (Royal College of Psychiatrists, 2012; Schulze & Angermeyer, 2003), and our interviews did not shed any further light on this.

Some lived experience participants reported ongoing symptoms despite compliance with medication, in terms of fluctuation and relapse, as well as experiencing ongoing, but manageable, positive symptoms.

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<sup>17</sup> <http://www.rcpsych.ac.uk/expertadvice/treatments/antipsychoticmedication.aspx>



*Despite the medication I still have that symptom of delusions, or whatever you call that. You can't get that out of your head completely, you know.*

— Lived Experience

Though only one lived experience participant was not taking antipsychotic medication at the time of interview, several stated that they would prefer not to be taking it.

*Well, now I just say, the tablets will never be my friends. I would like to see anyone who says 'I like taking tablets'... But I accept it and I tell myself that they are helping me. They help me stay more or less stable.*

— Lived Experience

*I do want to come off them all the time, but it's not possible.*

— Lived Experience

Some had stopped taking medication in the past, but associated this with a worsening of their symptoms and in some cases to hospitalisation.

*Well, I do know that I can't go without my medication. We've tried that. Together with [my doctor], I didn't take the medication for two years under her supervision... ..and then I had the relapse. Again, triggered by what other people might call just little things. But for me it was something really serious and so I had a relapse. So she kind of let me know that I would not be able to go without medication, that'll just stay a distant dream.*

— Lived Experience

Non-compliance with antipsychotic medication is relatively common, something which can have implications for recovery, including in terms of work.

*If you are dealing with a schizophrenic person who is compliant, the conditions for getting them back into work are much more favourable than for someone, who just stops taking their medication, does not accept that they are ill. That's a big complicating factor with respect to work.*

— Employment Specialist

Common reasons for not complying with medication include feeling that the medication is not effective or poor self awareness of ill-health. Medication side effects have been identified as the primary reason for the high rates of discontinuation of pharmacological treatment (Lieberman et al., 2005; A. P. Morrison, Hutton, Wardle, et al., 2012). Side effects of antipsychotic medication are relatively common, and can be considerable – in some cases debilitating (DGPPN, 2006). Treatment decisions are often based on getting the balance right between relief from positive symptoms, and keeping side effects low.

*Side effects – well the aim there is to reduce them as far as possible or to find a drug that doesn't have that many side effects.*

— Social Worker



The lived experience participant who no longer took medication, described the medication side effects they had previously experienced. This was a driver for no longer taking medication, given the effect it had had on quality of life and wellbeing.

*I've not been taking any medication for a few years now. But for the first few years, when I was taking medication, I was extremely tired. I can't even remember what it was called, but it was a very strong drug, but I didn't work at that point. And I was extremely overweight, I remember that.*

— Lived Experience

Side effects associated with antipsychotic treatment include sedation, cognitive impairment, emotional flattening and loss of interest, lethargy and tiredness, along with physically apparent effects, tardive dyskinesia and rapid weight gain (Bevan et al., 2013; Moncrieff et al., 2009)<sup>18</sup>. Lethargy/tiredness and weight gain were the side effects most often mentioned by participants, while restlessness, mild chronic arthritis and gastritis were also noted.

*Ok, it's hard for me to get up in the morning, that's not changed, it's improved, and my sleep could be a bit better but because of the gastritis, that I mentioned before, I'm sure that's a side effect of the medication.*

— Lived Experience

*Yes, tiredness. I take them and then I might as well go straight to bed.*

— Lived Experience

Side effects of antipsychotic medication may appear to be quite similar to negative symptoms (e.g. lethargy and withdrawal), meaning that sometimes side effects of medication are mistaken for negative symptoms of schizophrenia.

*The problem is also that you cannot always sort out if the irritations are caused by medication or by the illness itself.*

— Employment Specialist

It has been suggested that in some cases the side effects of the treatment may be more detrimental to employment prospects than the symptoms, making the consideration of possible side effects integral to treatment decisions. Side effects might affect ability to do the job (e.g. lethargy and sedation), or might facilitate stigmatised attitudes – with the physical side effects providing visible evidence that someone is undergoing antipsychotic treatment (Schulze & Angermeyer, 2003).

*Well, I would say, you can see that I'm ill, if you look closely, I've been taking medication for 20 years. But I don't think that's bad. You'd notice it from my weight, perhaps, things like that.*

— Lived Experience

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<sup>18</sup> <http://www.rcpsych.ac.uk/mentalhealthinfo/treatments/antipsychoticmedication.aspx>

Rapid weight gain as a side effect also represents a risk for co-morbid physical health concerns, in the guise of obesity and type II diabetes (Connolly & Kelly, 2005) and cardiovascular disease (A. P. Morrison, Hutton, Shiers, & Turkington, 2012).

Though several lived experience participants reported having experienced side effects, these were not necessarily seen as a considerable problem in regards to work. This might imply that these individuals have achieved a good balance in their medication – managing with a low dosage. Given participants were selected on the basis of their active engagement with employment, it might be suggested that they would have an appropriate treatment regime in place, and/or a higher level of functioning as might be expected by those in employment.<sup>19</sup>

There appeared to be a broad acceptance among lived experience participants that any side effects experienced were a necessary part of treatment, and they were not necessarily marked out for discussion, or if they were their impact was played down.

*Well, I sometimes feel sick and have to throw up, but other than that, and well gaining weight, but otherwise I don't feel any side effects.*

— Lived Experience

*I don't really have any strong side effects, because I also don't know how it would be without them.*

— Lived Experience

#### **4.1.3.2 Psychotherapeutic Interventions**

The growth in the use of psychotherapeutic interventions for schizophrenia in recent years reflects the increasing recognition of the importance of psychological processes in psychosis and the value of improving coping strategies (DGPPN, 2006; Lepping et al., 2011; National Institute for Health and Clinical Excellence, 2009).

*There is more and more research into psychotherapy for psychoses. This is an area that has been rather neglected in the past and the fact that psychotherapy for psychoses is becoming more and more of a focus and is being researched more is, in my opinion, a very important development.*

— Psychiatrist

The DGPPN guidelines outline the following types of psychotherapeutic interventions as suitable for the treatment of schizophrenia: Psychoeducation, Cognitive Behavioural Therapy (CBT), Family Interventions, Social Skills Training, Cognitive Rehabilitation and Training, Psychodynamic or Psychoanalytic Therapies, Occupational Therapy and other talking therapies (DGPPN, 2006). In this section focus is given to psychotherapeutic interventions with the largest evidence base as relates to work outcomes and the interventions raised by study participants: CBT, Psychoeducation and Occupational Therapy.

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<sup>19</sup> Participants were recruited through IFD and BTZ services

Psychotherapeutic interventions are usually used alongside pharmacotherapy. Though some view psychotherapeutic interventions as an alternative to be used where symptoms have proven to be resistant to medication alone (A. K. Morrison, 2009), a wholly psychotherapeutic approach to treatment received little support in this study.

Cognitive Behavioural Therapy (CBT), a talking therapy, is the most commonly researched psychotherapeutic treatment for people with schizophrenia. Research indicates CBT can produce large clinical effects on positive and negative symptoms of schizophrenia (Howes, 2014; A. P. Morrison, Hutton, Wardle, et al., 2012; Rector & Beck, 2001). In terms of employment, CBT has been demonstrated to address low self-efficacy or self-defeating thoughts regarding individuals and employment, and is associated with improved employment outcomes (Lysaker, Davis, Bryson, & Bell, 2009). Other talking therapies are less well researched but may create similar outcomes (Jones, Hacker, Cormac, Meaden, & Irving, 2012).

Most lived experience participants had at some time undertaken psychotherapy, though they did not generally identify which type. Where such interventions were discussed, it was done so positively, including in relation to supporting employment.

*I was in psychotherapy at least for the first six or so months when I started that work. That was definitely a great support for getting a certain feeling of security.*

— Lived Experience

Psychoeducation (which can be distinct, or delivered as part of CBT), was raised by one participant, who highlighted its role in encouraging self-awareness and self-management. Psychoeducation has been associated with reduced relapse and readmission and with encouraging medication compliance (Xia, Merinder, & Belgamwar, 2011).

*The best thing was really that I had the opportunity in the hospital to participate in psychoeducation. That means we learnt how to deal with the illness.... Well, we learnt that you should take your medication, and what they do and that there are early warning signs and so on. That was, I have to say, quite progressive for the times back then.*

— Lived Experience

Psychotherapy is widely available in Germany, though the office-based system (as opposed to a centralised system) encourages variability in access, e.g. there is a considerably higher density of psychotherapists in urban areas than rural areas, despite similar levels of need (BundesPsychotherapeutenKammer, 2011). Limitations on the licensing for psychotherapy practice also impacts on access. This observation reflects a point raised by several experts about the variation in availability of and access to treatment across Germany, leading to disparities in terms of support.

*The point is rather, how diverse the available services are – maybe there is too much art therapy in a particular region and not enough psychotherapy, or maybe there are too many doctors, but not enough psychotherapists. Or maybe we have a wide range of services, but*

*nobody knows that they exist and how to access them. The most important thing is to have a diverse range of services that are easily accessible.*

— Occupational Therapist

Pathways into psychotherapeutic support (where it exists) are not always clear. One participant described being left to identify such treatment services themselves rather than being directly referred.

*When I was discharged from the day clinic, they of course recommended that I also get psychotherapy, but I felt too shy to make contact with them... I didn't feel like I had had a psychotic episode and schizophrenia, I wasn't aware of that, or how I could get help for myself.*

— Lived Experience

No data is available on the uptake of psychotherapy by people with schizophrenia, though one expert suggested that access is poor.

*When you get out the clinic they leave you alone, they send you back to your doctor. Your doctor might give you more medication, but usually you don't get psychotherapy. Many psychologists, psychotherapists would say 'Oh schizophrenia that's not an indication for my work, and I can't work with these people'. There are just a few in Cologne, maybe 2 or 3 out of 200 or 300 which offer services for people with schizophrenia.*

— Employment Specialist

The suggestion that people with schizophrenia are not seen as relevant to the practice of some psychotherapists, indicates that stigma has a role in the provision of such treatment. This expert was clear that in their experience; psychotherapists were less disposed to choose to take on someone with schizophrenia, especially given the high demand for their services.

*They are difficult to handle, if they listen to voices, they might be aggressive, its more difficult than someone with depression. If you're a psychotherapist making good money with people with depressions, why would you attend to someone with schizophrenia? They are overrun by people so they can pick out the people they like.*

— Employment Specialist

Even where psychotherapy was accessed, it was not thought to be particularly common that employment outcomes would be seen as part of this, nor would they necessarily link an individual into vocational rehabilitation support.

*[The psychotherapists or psychiatrists] say that you still have to be on the patients list. Oh you are too ill to work. So people get perhaps months and months of being cared for and being told that they are not good enough for work. And it depends on them if they say ah, we have all these vocational services, I will tell you how to get into these programmes. That would be, let's say 30% of all these people would do it or perhaps 50% in some areas but*

not 100%.

— Occupational Therapist

#### **4.1.3.3 Occupational/Work therapy**

Occupational therapy (*Ergotherapie*) is focussed on improving performance skills, competence in daily tasks and for undertaking meaningful leisure activities, as well as the maintenance or restoration of skills and abilities that are relevant to an occupation. Occupational therapists are seen as more *functional/practical* than psychologists, and though it is identified in the S3 guidelines as a type of psychotherapeutic intervention, given its relevance to employment it is discussed here separately.

*Occupational therapy, work therapy on a day-care basis, that's very important... a step-by-step approach towards the issues of work.*

— Employment Specialist

Occupational therapy is common in Germany, with the highest rate of practitioners in Europe (Council of Occupational Therapists for the European Countries, 2012), representing the biggest group of psychiatry based therapists. As with other medical services, this is paid for through health insurance and requires a medical prescription. It is usually provided through hospitals.

*If you become schizophrenic and are admitted to a psychiatric institution in Germany, you will receive more occupational therapy than psychotherapy. In terms of hours and personnel.*

— Occupational Therapist

Occupational therapy was not explicitly discussed by many lived experience participants, though at least half of them would have gone through such services on their way to the employment service through which they were recruited (see Case Study 2, page 104). One lived experience participant spoke highly of these services in enabling them to learn to better organise themselves and their work activities (for example, organising emails), and in terms of their self-confidence.

*Something that did help me a lot was that I had done ergotherapy before as an out-patient here in the centre and due to that I had more self-esteem and I knew, just try and see what you can do and it'll work out and in the end it does, anyway.*

— Lived Experience

*After my last stay in the day care centre here and the ergotherapy, I'm much more organised.*

— Lived Experience

Occupational therapy services are often well linked with other medical services – an occupational therapist we interviewed highlighted that hospital admission and psychiatrist visits are often driven by the occupational therapy programme, as they are well placed to notice changes in an individual's well-being and ability to participate in the occupational

therapy programme.

Case Study 2 (page 104) provides a model of where occupational therapy services and vocational rehabilitation services can be linked, though it is not clear how well transfer between services is managed in other contexts. This may be due in part to their being funded by different paying agents.

#### **4.1.3.4 'Help Systems' and Social Therapeutic interventions**

This type of psychotherapeutic support is more focussed on the non-medical, social, and work-related components of the care process (Frieboes, 2003), including systems and interaction. The goal is to improve the social situation of the individual. Occupational Therapy is sometimes described as a type of socio-therapy (Reker & Eikermann, 1997), as are other work-related programmes.

It is often provided in the community, as out-patient treatment<sup>20</sup>. Provision usually involves multi-disciplinary teams, possibly including social workers, specialized nurses, psychologists and occupational therapists, as well as psychiatrists/social psychiatrists (DGPPN, 2014)<sup>21</sup>. Though they may overlap, socio-therapy is developed to be distinct from multidisciplinary in-patient care, assertive community treatment, community care provided by social workers or community psychiatric nurses, and family interventions (Frieboes, 2003). Day hospitals, night clinics and transitional institutions may all form part of socio-therapy provision. Socio-therapy services are prescribed by physicians, to be approved by the MDK.

The S3 guidelines highlight the value of socio-therapeutic services for employment promotion and vocational rehabilitation. Expert interviewees noted training and motivation methods, and coordination measures. The value of the services and the need to increase access and funding was noted by a few expert participants.

*Socio-therapy – that's still receiving way too little attention in Germany, it's not practiced much and there's a shortage in out-patient services. We have considerable deficiencies in this respect, but that would also be important.*

— Employment Specialist

Access to socio-therapy is more limited than the treatments described above, though it has been identified as highly used by people with schizophrenia. It was also less easy to define – lived experience participants did not explicitly mention socio-therapy, and it was difficult to identify if they had undertaken interventions which might fall under this banner, particularly given they are relatively new. Research on the role of socio-therapy in health or employment outcomes was not identified.

### **4.1.3 Summary**

Many areas of the health system and healthcare provision are likely to have influence on employment for someone with schizophrenia – including, timely access to services,

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<sup>20</sup> [http://www.mds-ev.de/media/pdf/BRL\\_Soziotherapie.pdf](http://www.mds-ev.de/media/pdf/BRL_Soziotherapie.pdf); [http://www.g-ba.de/downloads/62-492-5/RL\\_Soziotherapie\\_2001-08-23.pdf](http://www.g-ba.de/downloads/62-492-5/RL_Soziotherapie_2001-08-23.pdf)

<sup>21</sup> <http://www.asb-bremen.de/unsere-dienstleistungen/seeelische-gesundheit/soziotherapie/>

decisions around appropriate treatment, and professional attitudes and awareness.

Recent years have seen encouraging shifts in mental healthcare, away from in-patient and residential services, towards out-patient and community activities. Similarly there has been wider acknowledgment of the benefits of multi-disciplinary teams and early intervention services, though many barriers still remain.

A further difficulty identified is around the ability, or inclination, of healthcare providers whose services are funded by health insurance, to consider outcomes such as employment in their treatment decisions. There are also difficulties linking patients into non-medical rehabilitation services, which are funded differently.

Participants with schizophrenia and other experts generally felt that medication was a critical part of managing their health condition at work. Medication appeared well tailored for this sample, consisting of individuals who were participating in the labour market, though not all were happy to be taking it. The low reporting of side effects in the lived experience interviews might imply that dosages are relatively low in our sample group, which might support ability to work, though there was also a tendency to note relapses and time off work sick implying that the condition was not being completely controlled. There was also a low tendency to report negative symptoms.

Reflecting the evidence, an approach consisting of both medication and psychotherapeutic intervention was recommended by study participants. Though the extent to which psychotherapy is accessible to people with schizophrenia, whether due to lack of services in an area or lack of inclination to provide them to someone with schizophrenia, was a clear concern – particularly considering the important role which evidence indicates psychotherapy has in terms of employment.

Despite being in the S3 guidance and discussed positively by experts, access to socio-therapy interventions through the health system also appeared limited. This disconnect between the variety of services available and the reality of access to them across a large, regionally governed country was clear throughout the interviews.

Occupational therapy was reported as common in Germany, supporting the notion that recovery is broader than just recovery from symptoms. It was not clear however, whether open employment is a goal of medical treatment and rehabilitation. In particular it seems there are gaps in transition between health funded treatment and rehabilitation services, and vocational rehabilitation services funded by other bodies, meaning that despite being widely available, occupational therapy might not be leading to desired employment outcomes.

## **4.2 Disability employment policies and welfare**

A range of labour market activation policies exist which aim to encourage and support the employment of people with disabilities in Germany. Many of these focus on employers – creating demand for employers to employ people with disabilities and encouraging retention, as well as providing financial support to individuals to help them to work. These include:



preferential access to job vacancies, an employment quota system, flexible incapacity benefits/disability pension (allowing for part-time work), special tax deductions or exemptions, flexible work arrangements, personal work assistance, transport support, technical aids and housing/mobility benefits (European Commission, 2011). These can be seen as complementing ‘work integration’ services, which provide in-work support to employees with disabilities – discussed in section 4.3.

Eligibility for many services and supports is dependent on being registered as ‘severely disabled’<sup>22</sup>, i.e. having a degree of disability of at least 50 per cent, as determined by the Integration Office. Those with lesser degrees of disability (between 30 and 50 per cent) who have difficulty finding employment may also apply to the employment agency for equal status to that afforded to the severely disabled (*gleichgestellt behinderter Mensch*) (Kock, 2004). Those who qualify as severely disabled can obtain a pass (*Schwerbehindertenausweis*) from the Integration Office which verifies their degree of disability, and therefore their eligibility for support.

This section is focussed on policies for people with a disability pass, though it is noted that many people with schizophrenia may not have a disability pass. Of the estimated 7.5 million people in Germany registered as having a severe disability<sup>23</sup>, an estimated 11 per cent have mental and emotional disorders, and 207,565 have schizophrenia<sup>24</sup>, with many more likely to be in the 30-50% category.

*I’ve had a disability pass since the late nineties, because at some point that was a condition for me getting a certain job, that was in the catering business, so I’ve always mentioned that in subsequent jobs.*

— Lived Experience

Employers are entitled to ask a job applicant if they are severely disabled, and have the right to void the employment contract if the employee is disabled and did not disclose that they are when asked. A disability pass does not indicate the nature of the condition, meaning that an individual does not have to disclose their specific health condition to an employer. This may be beneficial where there is a high stigmatised condition (such as schizophrenia), the knowledge of which may influence employment decisions.

*So in terms of the consequences [of having a disability pass], it doesn’t matter what kind of disability a person has.*

— BMAS Civil Servant

It is also noted that though the policy and provisions discussed below are national, as described by a government official, the federated German system allows for considerable

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<sup>22</sup> The legal definition of disability is “when bodily functions, mental abilities or mental health deviate, for more than six months, from the condition typical for a given age so that participation in society is impaired” (Bundesministerium für Arbeit und Soziales, 2014).

<sup>23</sup> <https://www.destatis.de/EN/FactsFigures/SocietyState/Health/DisabledPersons/Current.html>

<sup>24</sup> [https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/Schwerbehinderte/2130510119004.pdf?\\_\\_blob=publicationFile](https://www.destatis.de/DE/Publikationen/Thematisch/Gesundheit/BehinderteMenschen/Schwerbehinderte/2130510119004.pdf?__blob=publicationFile) (page 12, number 58)



differences in the way policies are implemented by different *Länder* (states).

*We are responsible for the law and the Länder execute them... which means there are differences between the Länder. Well, they do talk to each other, but in the end each Land can set their own priorities, so you can't say that someone who gets a certain subsidy in Cologne will get the same in Hamburg. In general the same things are available everywhere, but if they maybe get €100 more or less, that's where the regional differences lie, but it also depends on the concrete situation in a certain area.*

— BMAS Civil Servant

#### **4.2.1 Employers: Incentives, compulsion, and support**

Several policies seek to encourage (e.g. through compensation), or even to compel employers to take on and retain employees with health conditions or disabilities, while others may be seen as enabling employers to provide better support to those employees, to allow them to remain to work and to work productively. Such policies seek to allay employer concerns about employee productivity as well as around what type of support they can provide to employees.

Such policies are underpinned by the social code (Part 2, Book IX) and reflect the premise of the General Equality Act 2006 which protects disabled persons against discrimination in working life as well as in public and private law. These policies include employment quotas, protection from dismissal, and workplace adjustments (all of which are discussed below), as well as preferential access to vacant jobs, the provision of in-work 'disability managers' (who offer counselling, assistance and technical support) and elected disabled employee representatives (Waldschmidt, 2009). There is also provision for special arrangements for sick leave measures (European Commission, 2011; Waldschmidt, 2009), such provisions are generally managed through Integration Offices, whose role is the support of severely disabled people in their working lives, and to a lesser extent the National Employment Agency (*Bundesagentur für Arbeit*), which pays for most vocational training measures, wage subsidies and employment benefits.

As suggested in Chapter 3, many barriers to employment exist for people with schizophrenia, often driven by stigmatised attitudes towards about an individual's capability, capacity and temperament, reducing employment outcomes for people with schizophrenia (as well as many other health conditions/disabilities). Though increasing recognition of mental health as an employer issue in Germany may be reducing the impact of stigma, this discourse is more commonly focussed on depression and "burnout"/stress than on psychosis, meaning we are unable to gauge whether this has had benefits specifically for those with schizophrenia.

This section is written with the caveat that we were unable to recruit employers from the open labour market for this study. Two employers were however recruited from the supported employment sector – one in an IFD, one in a social firm. Consequently we are limited in our analysis of employer need and practice. Suggestions from expert participants (including supported employment employers) as to why employers might be reluctant to

participate, included stigma around schizophrenia, a general nervousness among employers around participating in research, or that schizophrenia is too specific a subject given it is relatively rare in the working population, and that is rare that it would be disclosed by workers (even where there is a disability pass).

#### **4.2.1.1 Duty of employment quota – *Beschäftigungspflicht für Arbeitgeber***

A quota-levy scheme, introduced in 1974, requires that all organisations with a workforce of 20 or more must fill 5 per cent of their jobs with employees registered as severely disabled. Employers who do not fulfil the quota must pay a monthly levy (Kock, 2004), with the amount staggered depending on level of compliance<sup>25</sup>. In 2005, an estimated 27 per cent of employers (down from 39 per cent in 2002) did not meet the 5 per cent obligation (Waldschmidt, 2009; Waldschmidt et al., 2009). In 2011, BMAS reported employers were averaging 4.5 per cent employment – an increase on 4 per cent in 2003, but no change on 2006. Income collected through the levy is used to finance vocational rehabilitation services, including IFD, social firms, and workplace adjustments.

Employers who meet the quota may also be able to access salary subsidies for severely disabled employees of up to 70 per cent for a limited time period (Kock, 2004). Such subsidies are seen as a helpful measure in supporting new job seekers in particular. The amount and duration of wage subsidies has been reduced in the past few years.

*So for example if a person is not able to carry out their regular work duties due to a disability, then the employer can get subsidies if they nevertheless continue to employ this person, in other words – compensation.*

— BMAS Civil Servant

Expert interviewees were positive about the quota for many reasons. One suggested that it increases the chances of working with someone with a disability, including with schizophrenia, and consequently might help break down misconceptions about these conditions – changing employers' (and colleagues') attitudes in the future.

Some experts suggested that the quota did not go far enough, suggesting the option to pay the levy should be removed.

*[The situation should be] that the employers are required to employ these people and keep them, and not to have the option of paying some kind of fee in order to avoid employing people with disabilities.*

— Social Worker

No information was available as to the extent to which the levy supported the employment of people with schizophrenia specifically. Although achieving compliance to the extent of the 4.5 per cent implies that employment quotas have been a success, no further information is available on the quality of employment.

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<sup>25</sup> 105 EUR where 3-5% severely disabled employees in workforce; 180 EUR for between 2-3%; and, 260 EUR for below 2%.

#### **4.2.1.2 Protection from dismissal**

Those with a disability pass who have been employed for six or more months are afforded 'special protection against unlawful dismissal' (Sections 85 et seq. of Book IX of the Social Code). Employers must make an application to the local Integration service (the IFD), who will assess the case and make an official statement on whether the dismissal is justifiable. In the case of multiple redundancies, candidates are considered in terms of four criteria: age, tenure, alimony/support obligations, and disability status, with those who are ranked as the 'socially strongest' (i.e. younger, fewer support obligations, not disabled) the first to be made redundant.

Employers also have an obligation to offer a disabled employee another suitable vacant job in the company or to rearrange their current role if they can no longer perform their job because the severity of their disability has worsened.

Where the IFD rules that the dismissal is not justified, employment is maintained. Creating such barriers to dismissing employees with disabilities is thought to drive employers to take a more active role in supporting employees to remain in work and to work productively. Indeed, the IFD can provide ongoing support to the employer to assist retention. Such 'work integration' support from the IFD is discussed in section 4.3.

*Some just want to get rid of people, and if they don't get rid of them, they cooperate. This year I had a big company, they wanted to get rid of a lady, and when they saw they couldn't manage it, they cooperated.... But most of the companies are glad to get the support, that someone comes and helps them and explains what they could do.*

— Employment Specialist

However, despite being nationally available, awareness of IFD work integration services may not be high among employers (European Commission, 2011), possibly reducing the positive potential of this policy.

*I think that's what I would tell people, that there are people who come into the companies to support these people on the open labour market, so that they know about that.*

— Employer, Social Firm

*The IFD they are the good ones to say you can ring me anytime, I am on your doorstep tomorrow morning.*

— Occupational Therapist

In practice, the IFD very rarely denies the request for dismissing an individual – with only a quarter of all cases resulting in job retention (European Commission, 2011). Economic reasons are often cited as the reason why dismissal is justified (Doose, 2012).

In interviews it was further suggested that this protection has had the perverse effect of making some employers falsely believe that someone with a disability cannot be dismissed at all, thus creating a further barrier to employing people with disabilities (Doose, 2012;

European Commission, 2011).

Again, no data was available specifically for individuals with schizophrenia. However, though the provision offers some protection to individuals, its efficacy is unclear, particularly in times of economic difficulty.

#### **4.2.1.3 Company integration management**

Since 2004 all employers in Germany are legally bound to offer company integration management or BEM (*betriebliches Eingliederungsmanagement*) for employees who have been continuously or repeatedly incapacitated for work for more than six weeks within a year (Section 84 SGB IX, Book 9 of the Social Code). The objective of this law is to support work retention through increasing employer responsibility to help their employees to return to work, be it in their previous job or different duties, after long-term sickness absence.<sup>26</sup>

Employers are supported in developing and implementing integration management by the health and pension insurers and local integration services (IFD). An online resource exists for sharing case studies of work conducted under BEM<sup>27</sup> known as REHADAT (see Box C).

For those with mental health conditions, support often entails reorganisation of work, reduction of working time, transition into another job, change of the job description, medical rehabilitation, or technical or financial support. Further qualification or vocational training may also be offered (sometimes supported by a BTZ) (LVR-Integrationsamt, 2011).

Even though employer awareness of BEM has increased over recent years, the rates of actual implemented integration management strategies show room for improvement, likely due to a lack of legal mechanism to support this. Only 68 per cent of large businesses, 38 per cent of medium-sized enterprises and 28 per cent of small businesses offer return to work strategies (Vater & Niehaus, 2013).

Increased awareness of mental health conditions in the working age population has led to calls for starker cooperation with external support institutions regarding BEM. Many companies feel unable to manage a perceived increase of employees with mental health conditions in the future<sup>28</sup>. Small and medium sized enterprises have found the BEM particularly difficult to implement, being less likely to have a health and wellbeing strategy in place, and having less internal expertise on the management of chronic conditions and return to work. From an administrative perspective, having multiple funding bodies instead of a central point of contact is also seen as problematic (Ramm et al., 2012).

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<sup>26</sup> <http://www.neue-wege-im-bem.de/>; <http://www.bmas.de/DE/Themen/Arbeitsschutz/Gesundheit-am-Arbeitsplatz/betriebliches-eingliederungsmanagement.html>

<sup>27</sup> <http://db1.rehadat.de/rehadat/Reha.KHS?State=340&Db=1&SUC=Eingliederungsmanagement&SORT=P08>

<sup>28</sup> A report of the foundation Hans-Böckler-Stiftung (Freigang-Bauer & Gröben, 2011) stated that it remains a major information and implementation deficit in the SMES, which often had not dealt with BEM yet and/or lacked specialised staff in the company responsible for this matter. [http://www.betriebliche-eingliederung.de/global/show\\_document.asp?id=aaaaaaaaaahscz](http://www.betriebliche-eingliederung.de/global/show_document.asp?id=aaaaaaaaaahscz)

### **Box C: REHADAT – vocational integration advice for employers**

REHADAT is an information system about the vocational integration of disabled people in Germany, it is used by professionals and experts in the field, as well as by disabled people and other interested parties. It is funded by the [Federal Ministry of Labour and Social Affairs \(BMAS\)](#) and was developed by the [Institut der deutschen Wirtschaft Köln](#) (Cologne Institute for Economic Research). The use of REHADAT is free of charge. It provides detailed information about different aspects of vocational integration covering the following main points, each of them in a database format with interlinks between them:

1. Technical aids available in Germany for people with disabilities ([REHADAT-Hilfsmittel](#))
2. Case studies on successful vocational integration measures for disabled individuals ([Praxisbeispiele](#))
3. Specific literature on vocational training, employment and vocational rehabilitation ([REHADAT-talentplus](#))
4. Research projects (ongoing and completed) on vocational rehabilitation and integration of people with disabilities – in cooperation with the Bundesarbeitsgemeinschaft für Rehabilitation (Federal working group for rehabilitation of Germany) ([REHADAT-Forschung](#))
5. Relevant addresses, serving as directory for rehabilitation services, as well as vocational and social integration institutions and directory of Workshops for people with disabilities (WfbM) and blind people ([REHADAT-Datenbanken](#))
6. ELAN Software on Ausgleichabgabe to support employers ([REHADAT-Elan](#))
7. Applicable and relevant laws and legal regulations on vocational rehabilitation and integration of people with disabilities – in cooperation with the legal information system, Juris ([REHADAT-Recht-Datenbank](#))
8. Seminars for supporting the vocational rehabilitation of people with disabilities in their daily work ([REHADAT-Bildungsportal](#))
9. Statistics on people with disabilities and employment, vocational rehabilitation and integration ([REHADAT-Statistik](#))

#### **4.2.1.4 Workplace Adjustments**

Related to this is the responsibility for employers to provide disabled employees with “*Arbeitsassistentz*” (work assistance) in the form of “*Arbeitsplatzanpassungen*” (workplace adjustments) or “*Arbeitsplatzgestaltung*” (workplace engineering).

Employers are legally required to provide such adjustments, their purpose being to support an employee and optimise their work. Ongoing support in identifying and financial support for making adjustments can be accessed via the IFD.

In general adjustments are simple and not costly – for example, changes to the workload, tasks or introducing flexibility in working hours are often identified as particularly helpful. As

one expert suggested, emphasis is on creating working conditions which support self-management.

*Arranging the workplace in a way that the person can regulate the stress and pressure there themselves.*

— Psychiatrist

In this research, lived experience participants had not sought much in the way of workplace adjustments, placing emphasis on their being treated the same as other employees as much as possible.

*What kind of support I have received? Well, I'm not being wrapped in cotton wool, but I'm being treated like every other colleague.*

— Lived Experience

Reductions to hours, flexible hours, and the ability to take time off at short notice were the adjustments most commonly raised by participants (with some receiving welfare support as well).

*I can be on my own if I need to and take breaks and also mini-breaks in between.*

— Lived Experience

*It's not a problem if I start at half ten or ten. Or I can work in the afternoon or over lunch, if I want to... Sometimes it also happens that I don't feel well, that I have to ask my boss, can I take a day off in flexitime, and that's usually no problem. That's really great. I'm really pleased that there is this flexibility, this freedom and that's also a huge part of the quality of work for me personally, this freedom that my boss grants me.*

— Lived Experience

An employer at a social firm described how they had incorporated flexible working across their organisation, responding to the range of health needs found within their workforce, to optimise their productivity.

*There are of course people who say, oh my God, I can't do this or that, and then we can say, ok let's just try it, see how you get on with it and then we'll find a good arrangement. If we realise, for example, someone is able to be more productive in the afternoon when they are feeling better, or someone can take on additional mornings or some people can work full days, or we check out how many hours they can work at all. We have different models ranging from 15 hours per week up to 37.5.*

— Employer, Social Firm

In some cases, adjustments may mean identifying and managing the elements of the job that have been identified as triggers for poor health. For example, several participants saw deadlines as a trigger, which consequently their employers tried to avoid.

*So I have to keep working at it, but I'm not under time pressure to finish things for a certain deadline.*

— Lived Experience

*What we've never done is give her a task with a time deadline. I noticed that she can work very relaxed and sure-footed when she has no time deadline, when she's not under time pressure.*

— Employer, IFD

A key message, was that individuals and employers needed to work together to identify and manage triggers – for example, one interviewee reported that she was scared of being alone during late shifts, so her employer adapted this task for her. Self-management, and learning from errors and experiences featured throughout the interviews, with participants and their employers seeking new, improved ways of doing things.

*You can learn from bad experiences that happen to you, you can learn and develop from that. I agree very strongly with that.*

— Lived Experience

Indeed, being treated normally, having freedom and autonomy as other colleagues would was very important – one participant in particular discussed how they had developed ways of managing their condition at work by identifying difficulties and formulating ways to counter them.

*I've made it a habit to get some good safety procedures into my day, to see, what will I do first, what makes sense, so I work that out myself, i.e. my boss doesn't really tell me what to do. That's just like a normal workplace, just as a normal modern workplace.*

— Lived Experience

Examples provided included making sure emails were filed and labelled with project codes to allow them to be found easier, and building in feedback loops and double-checking requirements to look for any errors. One employer also allowed an 'opt out' option – ensuring the individual has the freedom to say no when they feel their health is being compromised.

*In the tasks, not in the workplace as such, she had to do everything. She also had to greet clients at the reception, she had to do telephone duty, i.e. taking calls, but always, she more or less always had the option to say, not today.*

— Employer, IFD

Having some in-work support to provide assistance through some aspects of the job was identified as valuable by expert and lived experience participants. This might be a formal job coach or mentor, or even just via colleagues or managers. It was described as someone who could let them know when they are doing something wrong, or to explain things in a different way when tasks are not at first clear.



*It's true that I need coaching usually at several points during the day... I say to [my colleague] I need your help, I need some structure, I don't know how to tackle this. So we sit down together, we go somewhere quiet and look at the task and it quite often happens that I come up with the plan myself how I could proceed, or sometimes that [they] say, well you could start by doing this, that could be a way. That's important.*

— Lived Experience

In order for this to work, the individual would need to feel able to discuss their health and needs with their employer. Creating an environment which is perceived to be supportive and facilitates open dialogue between employees and employers was highlighted by our employer participants.

*I just think that you have to learn to approach people with an open attitude and of course that you have to create a communication structure in your company that allows you to openly talk about these things, regardless of whether people are ill or not, that there is an open and transparent communication structure.*

— Employer, Social Firm

*Well, I can say if someone asked me "what do I need to consider?" Then I would say, listen up, I'll give you two pieces of advice. One is, make sure there is a relaxed working atmosphere, and two, make sure the person knows that they're allowed to be ill.*

— Employer, IFD

Indeed, perhaps more important than formal adjustments is the creation of a work environment in which the individual feels supported by the employer and has a good relationship with colleagues and particularly their line manager. This was highly valued by lived experience participants. Such factors are often identified as factors in 'good quality' work, and are often highlighted when discussing management of employees with any health conditions (Waddell & Burton, 2006).

*The attitude of the employer is very important and I find that a very central point; if you want to be successful in placing a schizophrenic person in the labour market, especially in the mainstream labour market, you have to invest a lot of time and effort into supporting the employers, because there is a lot of ignorance and also fear and our experience shows that the more you support the employer, the more secure the job is for the patient.*

— Rehabilitation Specialist

Both employers and lived experience participants highlighted the importance of communicating the value and the purpose of tasks to employees, to enhance understanding.

*The connection between "What do I do" and "Why do I do it", that you don't just put work on her desk and say, check it and put a date on it plus ten years, but that you explain why this has to happen.*

— Employer, IFD



Reflecting the findings around the role of work in recovery, the importance of making sure the individual knows their role and tasks have a purpose was emphasised – cementing an associated sense of self-worth.

*I'd have to say in our society, even though on the surface a lot has changed and improved over the last few years in terms of the stigmatisation of people with mental illnesses, I do think the people here regain a new kind of self-worth, and I think that's crucial, they have to feel their own self-worth again, that they are part of this organisation, that they are as important as the boss.*

— Employer, Social Firm

Those with experience of employing people with schizophrenia highlighted the importance of being open, aware and responsive of employees and their needs, taking into account health, social and personal factors (e.g. family commitments). Employers suggested that in some cases, employees might overstate their capacity, and suggested that sometimes expectations needed to be managed. .

*What I have learnt is that you have to ask people how much they can do. I mean the lady we're talking about, she always pops into my office before she starts work and then I see her facial expression, her posture, I ask "how are you?" and from all of this I deduce any potential restrictions on her ability to work for that day. But I talk about it with her then, so I say, if you want to go home, do that, and if you don't get your work done today, do it tomorrow.*

— Employer, IFD

*Some people overestimate how much they can do and say, I can do so many hours, that's when I tend to put on the brakes a bit and say, ok, let's start with a little bit less and if we then see that an increase is possible, than we do that.*

– Employer, Social Firm

Along with getting support, making adjustments, and creating open, honest, communicative environments, expert participants also highlighted characteristics that they thought important in an employer – these included, tolerance, a sense of humour, openness, and a positive, non-prejudicial attitude.

*But of course the main thing that I'd say again and again is that the first step is simply to say, yes, I want to, I'm taking this on and I want to try this and I'm not carrying around a bag full of prejudices, that's the main obstacle.*

— Employer, Social Firm

Employers must also be confident that they are not expected to be health workers – their role remains one of management. Even in environments where health support is a factor, such as in IFD and Social Firms, it is important to draw that distinction between work support and non-vocational healthcare.

*We are not a therapy facility here, I always stress that. We are a business, but we have this inclusive approach.*

— Employer, Social Firm

#### **4.2.1.5 Integration services (IFD)**

As alluded to above, a key role for the IFD is the ongoing provision of advice for employers on the management of employees with health conditions, including tailored support with identifying and funding adjustments. The services provided by the IFD were frequently raised as being a valuable source of help for employers seeking to support an employee with schizophrenia. However, IFD support may not be easily accessible to all employers.

Short-term contracting of IFD providers and financial cuts in different regions and areas impacting on service provision were all highlighted as barriers to service provision. These were raised as possible concern for employers, as they may not be able to rely on consistent support, which might return wariness at employing someone with a disability.

*They [the IFD] have to support not only the people with diseases but also the companies, the employers. They have to give them safety, "I'm with you if you have problems you can call me and I'm coming to help you", and this must be a stable and safe system, and the support, "I'm here for whatever problems". This has to be a stable and safe system.*

— Employment Specialist

IFDs also provide supported employment-type vocational rehabilitation services. These are discussed in more detail in section 4.3.3 and in Appendix 3.

## **4.2.2 Job creation and welfare**

Alongside encouraging employers to provide jobs in the open labour market and support people with disabilities to work within it, a range of policies have also been developed to support individuals that are seen as less able to compete in the labour market. This is mainly delivered through the development of new jobs and the provision of additional financial support, for example, disability pensions, which are provided to those who have substantially reduced capacity to work or are seen as unable to work resulting in early retirement. Mental health problems have become the leading cause of early retirement in Germany (McDaid, Knapp, Medeiros, & MHEEN Group, 2008). In the following sections we briefly discuss job creation schemes and the disability pension.

### **4.2.2.1 Job creation and marginal employment**

Numerous job creation schemes have been developed over the years to support increased labour market participation of people with and without health conditions. Shorter term initiatives focussing explicitly on those with disabilities have also been introduced, such as "*Jobs ohne Barrieren*" (Jobs Without Barriers 2004 – 2010), "*Job-4000*", "*JobBudget*", and "*50000 Jobs für Schwerbehinderte*" (50,000 jobs for the severely disabled). Many of these have been evaluated, though data is not easily accessible – Waldschmidt et al. (2009) provide information on major programmes until 2009.

Although not targeted at individuals with disabilities, the flagship German workfare

programme, “*Ein-Euro-Jobs*” (One Euro Jobs), also known as “additional jobs” or “working opportunities with extra compensation”, warrants mention. In this model, those receiving unemployment benefits are provided with a job, from which they earn a little money (i.e. one or two Euros/per hour), received on top of their existing social security benefits (including benefits relating to accommodation and heating, with health, nursing care and national insurance continuing to be paid for). This is to facilitate active participation in the labour market, with the aim of encouraging transition into permanent paid employment.

It is not clear what proportion of participants in the *Ein-Euro-Jobs* programme have a mental health condition, though it is suggested that having a health condition or disability may decrease the likelihood of being placed in this programme (Hohmeyer & Jozwiak, 2008). In our interviews, *Ein-Euro-Jobs* were rarely mentioned, though Projekt Router (see Case Study 3, page 106) does utilise this as one of their funding streams. Where they were mentioned, they were seen as providing an extra option for those wishing to return to work.

*It is good and important that there are options, such as minor additional income, where people can be employed for 1.50 Euros.*

— Social Worker

Criticism of the *Ein-Euro-Jobs* programme centres on the likelihood of people becoming trapped in these low paid jobs, rather than being able to use them to transition into open, permanent employment. A similar criticism is levied at marginal employment jobs, such ‘Mini jobs’ (also known as 400 Euro jobs) and ‘Midi jobs’, also developed to support labour market integration of the unemployed, through the provision of low paid work.

In our interviews, some experts raised the lack of appropriate jobs, in particular part-time work, as a barrier to employment for people with conditions such as schizophrenia, lamenting that new opportunities have not been created.

*This market should be opened up again, for people who cannot work full time, who cannot take the pressures of a full time job, more opportunities for this kind of work should be created, but these have been cut more and more in the last two years, so that’s difficult.*

— Rehabilitation Specialist

For those registered with severe disabilities, income from part-time work can be supplemented by the reduced earning capacity pension, discussed below.

#### **4.2.2.2 Pension for reduced earning capacity**

The Hartz IV welfare reforms of 2003 included the conflation of benefits for long-term unemployed (*Arbeitslosenhilfe*) and for those with disabilities (*Sozialhilfe*) into one system, enabling people to receive welfare support to supplement a low paying or part-time job. There is also provision for early retirement through receipt of a disability pension, supporting someone to prematurely leave the labour market due to health reasons.

*God, no, the only thing that was talked about was that he couldn't work! My brother and me, we tried for ourselves to provide a bit of structure for [him] and also income..... Every time [my brother] or I spoke to the doctors, they said, he won't ever be able to work. And [he] was advised to apply for disability pension.*

— Carer

Disability pensions are available to those who have not yet reached retirement age, but are seen as unable to work or have a reduced earning capacity due to their level of 'invalidity'. There are two types of disability pension (Rüb & Lamping, 2010): those unable to work more than three hours a day who are unable to find a job on the open labour market (i.e. not in sheltered work), qualify for the 'full' pension for reduced earning capacity (*Arbeitsmarktrente* or labour market pension); there is also an 'occupational disability pension' for those with partially reduced earning capacity, i.e. those who are able to work between three and six hours a day. For this latter group, 50 per cent of the pension can be received alongside the earnings from a part-time job<sup>29</sup>. If there is not an appropriate part-time job, individuals can receive the full disability pension (Rüb & Lamping, 2010). Such jobs may include marginal employment jobs described in the previous section.

*I've nevertheless had four psychotic episodes since 1993, smaller ones, but they did lead to me being off sick and I was very happy to be in a good work environment, I am very lucky to be able to do that. I'm on 50% pension, I have a severe disability grade of 50%, but I know that I have many healthy aspects within me, especially physically I'm healthy.*

— Lived Experience

Referral to the disability pension was suggested to be relatively common for people with a schizophrenia diagnosis. Mental health problems have become the leading cause of early retirement (McDaid et al., 2008). In 2009, 64,469 of all new pensions due to diminution of ability to work were due to mental and behavioural disorders – 38 per cent of all new pensions<sup>30</sup>. Almost 5 per cent of all new pensions were for schizophrenia, schizotypal and delusional disorders – a disproportionately high level considering the size of the population with such conditions is estimated at around 1 per cent. Putting this in perspective however, we note that a study looking at employment and schizophrenia in Germany, UK and France, identified that Germany had higher employment rates of people with schizophrenia who supported themselves entirely through their own earnings without recourse to state benefits (8.9 per cent in the UK, 7.6 per cent in France and 11.8 per cent in Germany), as well as a higher proportion who are working *and* receiving benefits (Marwaha et al., 2007).

The average entry age into pensions because of diminution of ability to work in terms of Statutory Pension Insurance ranges from a population average of 52 years, to 49 years old for those with mental health condition, to just 41 years old for those with Schizophrenia,

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<sup>29</sup> <http://www.working-in-germany.com/pension-for-reduced-earning-capacity-0076.html>

<sup>30</sup> Statutory Pension Insurance, new pensions because of diminution of ability to work (number/per 100,000 actively insured persons). Classification: years, Germany, age, sex, 1. diagnosis (ICD-10), pension fund organization. Available from: <https://www.gbe-bund.de/>

schizotypal and delusional disorders<sup>31</sup>. Out of the 4,493 per 100,000 people aged under 30 who received a new pension because of diminution of ability to work, 1,044 per 100,000 had a schizophrenia related condition – by far the biggest condition group<sup>32</sup>. This was reflected in our sample – one participant, aged 46 at the time of interview, spoke of already having obtained early retirement status some eight years prior.

[Interviewer] *How long were you off sick when you were ill?*

[Participant] *For a very long time, and it was the same in 2006-2007, but at that point I received “Hartz IV” and then I was put in early retirement.*

— Lived Experience

Such figures reflect the suggestion made in expert interviews that early retirement was being recommended and awarded to much younger people with schizophrenia. It was suggested the impetus behind this was to give an individual time away from the labour market to recover, with the intention of their returning when they are well enough. In reality however, it is suggested that many get trapped outside of the labour market.

*Well, the latest thing is that we send people into medical rehabilitation and the next thing I hear is that the medical rehabilitation has recommended to apply for a pension. There are more and more young people who receive pensions, and once they are out of the system, whether it is a fixed term pension, that's usually the case in the beginning, that has never... almost never the desired effect, that by staying at home for a year or two they recover and then find their way back into work. In my opinion that makes it even harder for people.*

— Social Worker

One expert suggested that this was particularly true where schizophrenia was concerned, whereas for other health conditions a move into rehabilitation is more likely than a move onto disability pension.

*Our approach is too institutional and generally a person with psychosis in this country will not have rehab first and the old age pension or disability pension second, but generally, people will have their disability pension first and will not have formalised job rehabilitation. Whereas people with other problems, such as addiction problems are likely to participate in rehabilitation programmes. People with psychosis are in a severely disadvantaged situation regarding job rehabilitation.*

— Psychiatrist/Academic

Another experts described how the eligibility regarding hours of work for reduced capacity pensions also meant that someone becoming ill could easily slip out of the reduced capacity pension system and into social care, from where it would be very difficult to return to the

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<sup>31</sup> Average entry age into pensions because of diminution of ability to work in the Statutory Pension Insurance. Classification: years, Germany, sex, 1. diagnosis (ICD-10), pension fund organization. Available from: <https://www.gbe-bund.de/>

<sup>32</sup> Statutory Pension Insurance, new pensions because of diminution of ability to work (number/per 100,000 actively insured persons). Classification: years, Germany, age, sex, 1. diagnosis (ICD-10), pension fund organization. Available from: <https://www.gbe-bund.de/>

open labour market.

*It's the same with people on welfare benefits when they are ill. Because the job centres always demand that you attest that they can work three hours per day, because otherwise they are immediately shunted off into basic social care. And then we end up with people who are barely 20 years old on basic social care. They'll never find a way into a working life. The only thing you can do for them is maybe a place in a sheltered workshop or a day care centre.*

— Social Worker

The pension being a 'default' option for someone with schizophrenia was highlighted in lived experience interviews – with one participant seeing this as making it easy for people to feel unsupported and to fall away from the labour market.

*Nowadays, it is very easy for people to accept a pension and I think that's wrong. I think the way it should be is that people are told, we'll do everything we can to make it work, if it doesn't work, you have the option of getting a pension, that's what I find important. But I don't believe in that being the default option, pension for over 50%, I don't believe in that.*

— Lived Experience

Those participants who discussed receiving the pension did not necessarily see it as a barrier to working, but there was some wariness about moving onto 50 per cent pension, with emphasis on the level of confidence required to enable someone to make the move back to work. The concept of a 'benefits trap' wherein people may fear that seeking to work would be too great a risk to their welfare payments, reflected similar findings in the UK (Bevan et al., 2013).

*The step towards work and the uncertainty... I couldn't be sure that this option of half pension, half work, that I would be able to do that and that would work. In the end, it worked out, but it takes a bit of courage, for sure.*

— Lived Experience

[Interviewer] *Does your pension prevent you from working?*

[Participant] *Well, yes, but that wouldn't be a problem. If I was feeling really well I would say, I'm feeling well, I can work and I have the confidence, but that's not the case. I wouldn't have any problem to give back the pension, if I knew that I could support myself and could take care of myself.*

— Lived Experience

### **4.2.3 Discussion**

A number of labour market and welfare mechanisms exist to encourage and support employment of people registered as having severe disabilities. Within the scope of this study and given the limitations to accessing condition specific data, it was not possible to identify the extent to which such mechanisms support the employment of people with schizophrenia specifically. We are able however to draw some general conclusions about the provision of

these mechanisms, and to consider this within the context of the broader employment situation for people with lived experience of schizophrenia.

Provisions on the employer discussed above aim to incentivise employment and support retention and effective working for people with disabilities. Though these were all discussed positively in principle, and the high rates of compliance with the quota implies success, our research uncovered various issues which will have particular implications for people with schizophrenia. These include the extent to which they create perverse disincentives for employing people with disabilities, such as fears there will be no flexibility if problems do arise, leading to employers picking out what might be seen as ‘safer’ health conditions – not thought to include such a highly stigmatised condition as schizophrenia. Though in-work support is available through the IFD to provide reassurance to employers (laudably funded by the quota-levy system), employer awareness of the IFD support was suggested to be limited, as was the ability to provide ongoing support on which employers might rely. The most common workplace adjustments are simple and cost free – many involving time flexibility and personal and professional support – implying that a source of reassurance and advice (such as via an IFD) on an ongoing basis would be of considerable use to allay employer concerns and facilitate communication, leading to the development of an appropriately supportive work environment.

It was not clear whether the creation of specific jobs to increase work participation for those who have difficulty finding work or who can only work reduced hours has had much impact on people with schizophrenia. Several lived experience participants were in part-time work with reduced earning capacity pension, but we lack a population perspective. Data on the success of job creation and marginal employment schemes in terms of participation and employment outcomes for people with health conditions would be valuable.

There was considerable concern about the extent to which early retirement and reduced earning capacity pensions were used as an “easy” route out of the labour market for people with schizophrenia, rather than taking a vocational rehabilitation route – particularly for young people who may not have had any opportunity to participate in the labour market before the onset of schizophrenia. Confidence was again identified as a barrier to moving into the labour market, even where 50 per cent pension would be available (should a job with appropriate hours be found).

As touched upon above, IFD can provide integration support in the workplace to aid job retention and promote effective working – supporting both existing and new employees. In the following section we discuss the role of the IFD in supporting employees with schizophrenia as well as looking at other vocational rehabilitation services that aim to improve work readiness, work ability and provide support for people with schizophrenia to find and enter work, and to work productively.

### **4.3 Vocational rehabilitation and work integration**

There is a variety of specific vocational rehabilitation measures for people with disabilities in Germany aimed at supporting people to return to, and remain in the labour market. Along



with vocational training programmes, many of which include participation in the open labour market as a goal, services provide ongoing support to integrate people into the workplace. Sheltered employment opportunities are also a common option.

Vocational rehabilitation (VR) is an idea and an approach as much as an intervention or a service – it may be seen simply as *“whatever helps someone with a health problem to stay at, return to and remain in work”* (Waddell, Burton, & Kendall, 2008). In the social code (Section 33, Book IX) vocational rehabilitation (*berufliche Rehabilitation*) is described as encompassing *“all forms of assistance needed to sustain, enhance, generate or restore the earning capacity of persons with disabilities or persons at risk of becoming disabled while taking account of their abilities. The ultimate aim is to ensure their permanent participation in working life wherever possible”* (Bundesministerium für Arbeit und Soziales, 2014).

Modern thinking about vocational rehabilitation is shifting away from compelling employers to take on people with health conditions as a duty. Instead increasing emphasis is on highlighting the prospective employees’ skills, education and experience, and their ability to manage their symptoms – to demonstrate how having a health condition should not be seen as a barrier to working.

*There are many many people nowadays who don’t understand vocational integration, they say “isn’t it terrible this employer doesn’t take these people” and so on. But what they do, they say “you know, he is ill, a person with schizophrenia, can you employ him?” This is completely wrong, it just sort of raises anxieties. But you have to say that they are skilled, that they are trained, they know how to handle their crisis. They might know how early onset of symptoms can be handled. They have their doctors and on top of it.*

— Occupational Therapist

VR encompasses a wide range of programmes, which take different approaches to prepare for and place individuals in employment, and to provide support to integrate people into the workplace, improving retention. The German system of VR is long-established and comprehensive (Waldschmidt et al., 2009) – growing in prevalence during the 1970s (Bramsfeld et al., 2004), and continuing to develop today (Doose, 2012). Germany has greater provision of formal vocational rehabilitation services and placements than many European neighbours. This includes a strong network of sheltered employment and particularly sheltered workshops (WfbM) (Waldschmidt et al., 2009) – which are still common despite reductions in such programmes in some other countries (Marwaha et al., 2007) – as well as social firms (*integrationfirmen*).

In the following section we will consider the evidence base for effective VR for people with schizophrenia, as well as the nature and effectiveness of current VR support identified as being commonly used by people with schizophrenia in Germany. This includes traditional Work Integration services, which provide in-work support in the open labour market, as well as sheltered employment options – workshops and social firms.

As identified throughout this study, the limited availability of data on service usage and about

particular health conditions/disabilities mean we cannot be sure of the extent to which people with schizophrenia are engaged with particular support provision, how successful they are in leading to employment outcomes, or their success comparative with the non-disabled population and other disadvantaged groups (Waldschmidt et al., 2009). Our research however provides a qualitative view of the situation, as identified through expert interviews, as well as from previous research.

### 4.3.1 VR and employment outcomes – reviewing the evidence

Traditionally VR has taken a pre-vocational approach to finding employment for people with health conditions and disabilities – training people first and then seeking to find a work placement. In recent years, a different approach has increased in credibility, known as supported employment, wherein competitive employment is sought as quickly as possible, and then additional in-work training and support is provided as required a ‘place then train’ approach.

Despite its widespread use, pre-vocational training has had poor success in achieving the goal of open, competitive employment for people with severe mental ill health, including schizophrenia (Burns et al., 2007; Waldschmidt et al., 2009). Considerably greater success has been found through use of supported employment, and in particular the Individual Placement and Support (IPS) approach (see Box D). A systematic review looking at studies where pre-vocational and supported employment approaches had been compared not only found supported employment to produce better employment outcomes, but also found no clear evidence that pre-vocational training was any more effective at getting people back to work than standard community care (Crowther, Marshall, Bond, & Huxley, 2001).

#### Box D: Principles of IPS

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.

A recent 5-year Randomized Controlled Trial (RCT) in Switzerland showed that the improved outcomes for IPS over traditional VR are sustained over the longer term. Participants in IPS were more likely to obtain competitive work, to remain in work for longer, to work more hours and to earn higher wages. The social return on investment was also higher – participants in IPS had fewer psychiatric hospital admissions, and spent fewer days in hospital. As time went by participants became less reliant on the IPS service to help them to retain their job (Hoffmann, Jäckel, Glauser, Mueser, & Kupper, 2014). The IPS model has been trialled in Germany – as part of a multisite randomized trial of IPS across six European locations (including Ulm), known as the ‘Enhancing the Quality of Life and Independence of Persons Disabled by Severe Mental Illness through Supported Employment’ or EQOLISE project

(Burns et al., 2007; Burns et al., 2009). In this study IPS was found to be more effective than the best locally available alternative service for every vocational outcome measured, including working more hours, working more days, more people being employed for at least one day, lower drop-out rates and lower hospital readmission rates (Burns et al., 2007). However, in Germany, where IPS was compared to a RPK residential service, employment outcomes were not significantly different when compared to 'usual' vocational services (Burns et al., 2007; Knapp et al., 2013).

Some models of VR found in Germany are similar to the IPS model – this is discussed in the following section. However, there are a number of barriers exist to the implementation of a full IPS model in Germany. The main barrier is the strict division of payment responsibilities of the different social insurance bodies – between health insurance, the pension fund, and the employment agency. This becomes particularly problematic in the case of an employee becoming ill and needing to go to hospital – in which case one of the above insurance bodies will be assigned as having payment responsibility at any one time. Though the pension fund pays for vocational rehabilitation, they will not pay for acute treatment in the case of poor health, this is the remit of the health insurance. However, health insurance is not responsible for work-related issues. One of the challenges for policymakers in this area is looking at how such barriers might be addressed in order to apply the best practice in this area.

The challenges for implementing IPS, as well as for achieving the best outcomes for people with schizophrenia within current VR provision, are discussed in section 4.3.3.

### **4.3.2 VR in Germany**

VR in Germany includes a range of services on the spectrum of pre-vocational to supported employment type services. A summary of mainstream VR services identified as the most relevant for people with schizophrenia is in Appendix 3. There are also a number of locally developed and run services (see case study 2, p104, for an example). A number of factors may influence which type of service an individual will go to. These will likely include the nature of the disability, the assessment of condition severity and distance from the labour market, as well as whether an individual is already employed and may be able to return to that job. The paying body will make a decision upon applications, based on assessed need and service intensity (with implications for cost). In reality, as discussed later in this section, this decision will also be influenced by several other factors – including stigma and attitudes, and awareness of and access to services.

Often occupational/work therapy is the first step towards returning to work. Though this may be the gateway into a VR service, many people with schizophrenia are able to return to the open labour market without further support (Reker & Eikermann, 1997).

*They can return straight back to their job after my work therapy. Usually people who already have a job. So they return to their workplace, perhaps within a step-by-step re-entry model with work therapy as the first step.*

— Occupational Therapist

Many others may require further support, and will progress into pre-vocational or supported employment services, whether through institutions (e.g. RPK) or in the community (e.g. IFD). Many VR services are high intensity, and usually last a period of twelve months, with the possibility of extension or movement into a different service, before moving into the open labour market or into sheltered employment – with a sheltered workshop seen as a common option for people with schizophrenia.

*A large proportion of severely mentally ill people will not be able to go to vocational rehabilitation programme after the work therapy, but they will go into a sheltered workshop.*

— Occupational Therapist

It is not known how many people with schizophrenia have found or retained employment with or without the support of such services in Germany. VR services were highly valued by those with lived experience of schizophrenia participating in this study, and were seen as important by experts.

*I had already tried a couple of times to find a normal way in [to work] and for one reason or another that never worked out. And that's why I went that way in the end.*

— Lived Experience

*I've never seen a case where a person with a severe mental illness has managed to integrate themselves into a workplace on their own. They will always need some kind of support.*

— Occupational Therapist

Participants in this study included those who had first undertaken occupational therapy, either as in-patients or as day patients before going into a VR service to facilitate progression into employment (be it a return to an existing job or seeking a new job). They were recruited through two different VR services (an IFD service and a BTZ-type service). Several participants were still receiving employment support in their work.

Along with acknowledging the role of occupational therapy, in terms of ongoing VR support, several expert participants also identified IFD and BTZ services as having a major role in supporting employment outcomes for people with schizophrenia.

Both IFD and BTZ services take an active approach to securing employment in the open labour market, and are seen as following more of a supported employment type model than pre-vocational. They both align with the European Commission (2011) definition of supported employment as “a scheme that supports people with disabilities or other disadvantaged groups in obtaining and maintaining paid employment in the open labour market”. The IFD model might be seen as closer to the IPS model than BTZ, due to the lengthy period of preparation required in the BTZ model, and the reduced ability to provide ongoing in-work support.

Most experts also raised sheltered employment options, both in the form of Sheltered Workshops and Social Firms, as having a significant role. Views varied among experts as to the value of both options for people with schizophrenia. Though in principle such options are intended to lead to employment in the open labour market, a tendency for this not to happen means they do not sit comfortably being described as supported employment, whilst their creation of an employed situation, albeit in a 'closed' labour market distinct from the usual labour market, means they similarly do not fit the pre-vocational classification.

The following section will consider the roles and use of specific supported employment services (IFD and BTZ) and sheltered employment options (workshops and social firms) in Germany for people with lived experience of schizophrenia. This will be followed by a discussion of how well current provision works for people with schizophrenia, highlighting the key concerns identified in this research.

Further information on all the services discussed can be found in Appendix 3.

### **4.3.3 Supported employment in Germany**

Supported employment for people with mental and physical health conditions has a long history in Germany, and is well-embedded in the VR system.

*When supported employment was "invented" we had already this system in Germany, but in research programmes this was not recognized because of language problems – it was said this new programme comes from USA/England and is not known in this country... I know that in the UK they are developing a lot of programmes similar to ours.*

— Occupational Therapist

Interestingly, this view wasn't shared by all participants – with some suggesting that there was progress to be made in Germany in terms of implementing the international evidence.

*There needs to be a quicker implementation of international research, for example on supported employment. Germany really is way behind on this, but there is clear empirical evidence that these programmes work, so they have to be established more quickly.*

— Occupational Therapist

This contrast of views was a theme within the study – with variation in both services awareness, and service provision identified throughout.

As noted above, IFD and BTZ services were identified as the main providers of supported employment for people with schizophrenia. Given the lack of available national data on service use or service outcomes for people with schizophrenia, it is difficult to ascertain whether these services are the most effective. The following sections provide brief summaries on these services, including data identified on use by people with schizophrenia.

It is noted that there are also many locally run, independent vocational rehabilitation operations in areas of Germany. Unfortunately it was not possible within the scope of this

study to explore the extent to which these services exist across Germany, nor the extent to which they support people with schizophrenia to achieve employment outcomes. Examples of such services are provided in case studies 2 and 3 (p104 and p106).

Since 2008, a designated funding stream has existed for the provision of a specific model of supported employment (*Unterstützte Beschäftigung* (UB)) services, outlined in §38a SGB IX. The funding is awarded through competitive process for local service providers, for a period of two years. Every organisation that undertakes services for BMAS is able to apply for UB (including through IFD, BTZ, and sheltered employers). In Germany as in other countries, UB/Supported Employment is more often associated with supporting individuals with learning difficulties. Given the evidence of the effectiveness of supported employment (the IPS model in particular) for achieving job outcomes for people with severe mental health conditions, this group is increasingly being seen as eligible for UB funded services. A 2011 survey conducted by the BAG UB (the federal working group for supported employment) registered 914 school leavers as UB participants, of which individuals with learning or intellectual disabilities were the main group (74.1 per cent), followed by people with mental health conditions (12.3 per cent) and physical/sensory disabilities (10.4 per cent) (Niehaus & Kaul, 2012). According to an expert interviewee, only a small proportion would have schizophrenia.

#### **4.3.3.1 Integrationsfachdienst (IFD) – Integration Service**

IFD provide integration support services to people with both physical and mental health conditions who have a disability pass. IFD is provided through local integration offices (*Integrationsamt*), with one per region. They operate on time-limited contracts, lasting a few years.

IFD provides two types of service – one concerned with finding and returning people to work (IFD-V) and the other with in-work support (IFD-B). The legally defined target groups are: (1) unemployed people with a severe disability and the need for support on the worksite; (2) people with disabilities working in a sheltered workshop; and, (3) young people with disabilities leaving school. However, it has been suggested that a priority of reducing unemployment has led to a shift in focus away from supporting those in school or sheltered workshops as these groups are not 'employed' and therefore not the concern of the National Employment Agency (which pays for most of the vocational training measures, time limited wage subsidies and unemployment benefits) (Doose, 2012). IFD are themselves employers of people with severe disabilities – in 2010 it was estimated that 9,000 out of its 25,000 employees were severely disabled (36 per cent, though the original aim was for 50 per cent disabled/non-disabled workforce).

IFD services are seen as particularly relevant for people with mental health conditions (Aktion Psychisch Kranke, 2007), with one expert stating that this was the original focus of IFD services. However, despite increasing demand for services by those with mental health conditions, they have been decreasing as a proportion of service users. Between 1998 and 2006 the proportion of people with a mental health condition receiving support from an IFD decreased continually from around 55 per cent to 25 per cent (Aktion Psychisch Kranke,



2007), dropping to 22 per cent by 2012 (BIH, 2013; Doose, 2012).

One IFD service we spoke to estimated that of their current client base of approximately 180 people with mental health conditions, about ten had schizophrenia. One IFD provider, having worked in the IFD for over 30 years was clear that in this time people with schizophrenia specifically had decreased as a proportion of service users.

A lack of data on specific conditions and limited data on outcomes mean that it is difficult to assess the effectiveness of IFD services in terms of employment and job retention outcomes – particularly given those with disability passes will be subject to other employment protection. One IFD service stated that they often achieved an improved work situation.

*I would say we [in the IFD] have 60-80 per cent success rate in getting the situation more relaxed [at the place of work] than before we came. This might be a positive view on my job, I'm not neutral.*

— Employment Specialist

Outcomes for the successful placement of people in jobs are even less clear. One IFD service suggested that cuts to their funding meant that they were no longer able to support people seeking work, but had focussed their attention almost completely on supporting people already in work to remain in work. This claim reflects other reports that decreases in funding, much of which is paid by employers through the duty of employment quota-levy scheme, has increased financial pressure on IFDs, leading some to limit their services (BIH, 2013).

#### **4.3.3.2 Berufstrainingszentrum (BTZ) – Vocational training centres**

BTZ provide vocational training for people with mental health conditions with prior vocational experience or training, to support their re-entry into the ordinary labour market or further training. In the majority of cases, BTZ re-train people to return to their current or previously held job, though in some cases they may train individuals for a new role, should their old role be seen as inappropriate for their health and abilities. The vocational training (or re-training) is undertaken over a 12-15 month period, usually including periods of time-limited internship to integrate employees into roles relevant to their employment aspirations. After employment has commenced, the BTZ also provide a period of support while in work, usually lasting 6-12 months.

There are 24 BTZ in Germany<sup>33</sup>. Funding normally comes from the pension fund (*Rentenversicherung*), the Employment Agency (*Arbeitsagentur*), depending on previous social security payments, or the employer's insurance should the condition be work related. As suggested above, funding streams such as UB may also be appropriated by BTZ services through a competitive process.

Data provided by two different BTZ (Rhein-Neckar and Hamburg), showed that 19 per cent and 25 per cent of their clients respectively had schizophrenia – implying that the proportion

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<sup>33</sup> <http://bag-btz.de/standorte/index.html>



of service users with schizophrenia may be higher in BTZ than in IFD. Employment outcomes across both services ranged from 50-60 per cent across all health conditions. Though poor availability of data means we cannot be sure, one BTZ service reported that people with schizophrenia had the best outcomes of all their clients.

*Up to 2011 we had the best re-integration outcomes [into open employment] for people with schizophrenia. Since 2012 the other diagnostic groups have improved and reached the same outcome.*

— Employment Specialist

It is further noted that the length and nature of the service makes BTZ an expensive option.

#### **4.3.3.3 Rehabilitationseinrichtungen für psychische Kranke und Behinderte (RPK)**

RPK (Rehabilitation institutions for people with mental conditions and disabilities), have good outcomes for employment for people with schizophrenia. RPK received limited attention in this research – as a residential service they do not fit comfortably in the supported employment model, and are consequently very expensive and therefore limited in availability. They are briefly raised here as RPK have been used as the comparable service in studies looking at the effectiveness of IPS in Germany – see Knapp et al. (2013). In this study, employment outcomes for those undertaking RPK (the “as usual” service) were similar to that gained through IPS – though costs of the RPK were considerably higher (almost four times as much). Further information on RPK and employment outcomes can be found in Appendix 3.

#### **4.3.3.4 Reflection's on IPS**

Many of the eight principles of IPS (see Box D, page 77) are reflected in the above services. Along with the overriding principle of supporting people into open, competitive, sustainable employment, both IFD and BTZ services provide individualised support and seek jobs as consistent with individual preference, skills, abilities and past experience. Support is provided through employment specialists (e.g. *IFD Integrationsberater/in*) who build relationships with employers and offer them support as well as individuals.

There are also differences. For example, IFD services are not open to everyone but only to those registered as disabled, while the BTZ does not move people to work quickly, involving a considerable period of training. Funding prevents both services from offering time unlimited support, while legal provisions and funding prevent the integration of employment support with clinical teams. Co-location of vocational and clinical services is often highlighted as an integral part of IPS, with outcomes of service provision relevant to both those working in health and employment spheres.

*In my view in Germany we try to establish not IPS but a kind of supported employment – because clinical and work-related vocational services live in rather separated worlds and IPS integrates medical staff.*

— Employment Specialist

This is perhaps more problematic in IFD, given that BTZ also have a medical rehabilitation arm and are staffed with psychologists and occupational therapists.

Individual BTZ and IFD services may build relationships with clinicians (such as psychiatrists) for their clients or in client referral, this is not a formal part of the structure and its dependence on individual services and client preference mean it is likely quite variable. It was suggested in interviews that both medical and vocational professionals should make more effort to improve their interaction, and that the value of building this relationship required greater emphasis, particularly in the medical system.

*I think the level of attention, the level of focus is not sufficient in our mental healthcare system ..... We also have this whole system of IFD, which is supposed to keep people in work. But the link between mental healthcare and the IFD service is not sufficient according to my experience. So we need more liaison work and more openness and more flexibility and psychiatry needs to look into the issue a lot more and forge links with the unemployment support system and local employers.*

— Psychiatrist/Academic

A further issue to be noted is in terms of access, though in principle BTZ is open to all and IFD to those with a disability pass, in reality access to services may be obstructed by a number of barriers – including complex, unclear referral pathways, poor awareness of the availability of appropriate services, and stigma about schizophrenia among referrers, funding bodies and within systems. These are discussed in greater detail in Chapter 5.

#### **4.3.4 Sheltered Employment: sheltered workshops and social firms**

Sheltered employment opportunities are a considerable provider of employment for people with disabilities and health conditions in Germany, and particularly mental health and cognitive conditions (Detmar et al., 2008).

Sheltered employment may be seen in two forms – sheltered workshops, known as WfbM (*Werkstätten für behinderte Menschen* – workshops for disabled people) and social firms (*Integrationsfirmen*). Both provide work opportunities which are protected for those with disabilities or health conditions, rather than in the ‘usual’ labour market. However, while sheltered workshops are seen as far removed from the usual labour market, social firms operate within it – so even though jobs are protected, the business itself must be competitive and operate in the usual labour market. Income in social firms is also reflective of the usual labour market, while sheltered workshops provide nominal salaries.

Criticism of sheltered employment options often focus on their level on inclusivity – particularly the extent to which disabled employees are separated from the non-disabled employees, and indeed what might be seen as ‘usual’ society.

*I'm a bit sceptical about social firms, I'm sceptical about the sheltered workshops – I'm sceptical about all these “special worlds” where you separate people from the usual way, and the usual places that people live. We have this new expression ‘inclusion’, and often*

*sheltered workshops, they are not very inclusive.*

— Employment Specialist

Despite such concerns, many feel that both social firms and sheltered workshops have a role in VR and should be retained as part of the employment offer for people who have difficulties entering the labour market. The strength of sheltered workshops in particular make them a key provider of employment, with some arguing that this is to the detriment of other employment possibilities.

#### **4.3.4.1 Sheltered Workshops**

Sheltered workshops (WfbM) are open to all people with disabilities, irrespective of the nature and severity of their impairment, who are capable of doing a minimum amount of economically useful work (Ward, Grammenos, Huber, & Rabemiafara, 2007). WfbM have a strong presence in Germany, though not as much as found in other European countries (Ward et al., 2007). WfbM is the second most common type of work participation for disabled people in Germany after work in the regular labour market (3-4 times as many work in the regular labour market) (Waldschmidt et al., 2009). In 2013, there were an estimated 682 “main WfbM”<sup>34</sup>, training and employing almost 300,000 severely disabled people – with numbers currently growing (BIH, 2013). Approximately 20 per cent of employees in sheltered workshops have a mental health condition, compared to three quarters with learning disabilities<sup>35</sup>. The proportion with mental health conditions has grown in recent years (Doose, 2012).

*These [sheltered workshops] are designed in general for people with mental disabilities, regardless of which type, so we have those sheltered workshops in Germany for people with disabilities, in which people with mental disabilities can find an occupation that is appropriate for their abilities.*

— BMAS Civil Servant

Though sheltered workshops do not provide open employment, they are identified in the social code (SGB IX 136) as having the goal of supporting participants to transition into the regular labour market, in that respect they may be seen as a form of pre-vocational training (Doose, 2012; Hoffmann, Jäckel, Glauser, & Kupper, 2012).

*Sheltered workshops ... should really be the first port of call before trying to reach the general labour market.*

— Betreuer

Transitions are supported in policy, for example Budget for Work (*Budget für Arbeit*) personal budgets may be used to subsidise wages where someone has transitioned from a sheltered workshop into an employed role. In practice however, such transitions rarely happen (Doose, 2012; European Commission, 2011), with those with higher or permanent support needs often completely excluded from accessing employment (Diakonisches Werk

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<sup>34</sup> <http://www.bagwfbm.de/page/24>

<sup>35</sup> <http://www.bagwfbm.de/page/25>

der Evangelischen Kirche in Deutschland, 2009). Data from BMAS shows that between 2010 and 2012 only 0.2 per cent of people with disabilities in sheltered workshops had transitioned to a job in the usual labour market.

*Sheltered workshops in Germany – they are a “comprehensive all-round no-worries package”. Also not very rehabilitative, once you’re in you can spend the rest of your life twiddling thumbs in those workshops.*

— Occupational Therapist

An alternative model is *Außenarbeitsplätze* (outsourced work places), wherein employees of sheltered workshops are ‘outsourced’ to companies in the general labour market, but retain their status as WfbM employee. This aims at providing a closer labour reality and feeling of taking part in the society. These are also quite rare – in 2006, only 3 per cent of all sheltered workshop places were conducted in external companies (Doose, 2012).

Transitions to from sheltered workshops into supported employment is also limited – the European Commission reported that in Germany, supported employment was not used for people who wish to leave sheltered workshops and enter the open labour market (European Commission, 2011).

There are many legal barriers to transitioning from sheltered workshops into the general labour market (Wendt, 2010). One barrier is the lack of incentives for the Federal Employment Office to support transitions – given that those in sheltered workshops receive payment via the welfare office, and individuals are not counted in unemployment figures (European Commission, 2011). One expert suggested that support for transitions was less common for people with mental health conditions. Indeed, during our research, one expert noted specific transitional services for those with physical health conditions (e.g. *Arbeit plus*<sup>36</sup>), but none was suggested for those with mental health conditions.

It was also suggested in interviews that individuals may be concerned about the risk to their reduced capacity earnings pensions should they seek work outside the sheltered workshop as there will be implications for the hours they are able to work as well as permissible earnings.

The idea of sheltered workshops has become increasingly the subject to criticism in recent years. In several countries their presence has decreased significantly, while in the UK they were phased out almost entirely in 2013 (replaced by ‘supported businesses’ or social firms). Workshops are detached from what has been termed classical liberal market mechanisms (Klinkhammer, Niehaus, & Menzel, 2012), operating within a non-competitive business model. They are expensive to run – with one expert suggesting that a place in workshop costs the state around 1000 Euros/per month (varying depending on location) while productivity is low.

Workshops have also been criticised for financially exploiting employees; wages are low –

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<sup>36</sup> More information: <http://www.boxdorfer-werkstatt.de/arbeitsplatz/#c192>

estimated at 180 EUR a month on average (Doose, 2012). It is noted that although wages are too little to sustain an independent living, they may be supplemented by the reduced earnings capacity pension.

The quality of the work is also a concern – with emphasis placed on activation or subsistence rather than employment (European Commission, 2011), this might be seen as running counter to the principles of supported employment, as well as evidence on the value of work for health. This was recognised by an expert interview, even where sheltered workshops were seen as having a role.

*Well people regain the best kind of self-worth when they get into fair and open employment ... as the word inclusion says, just as people without disabilities. So you receive the same kind of recognition. Of course, that's not always possible, that's why there are sheltered workshops for people with disabilities, and they are a very important area*

— Employer, Social Firm

It was suggested that changes would need to be made to the way sheltered workshops operate to provide appropriate services for the growing population of employees with mental health conditions.

*The numbers of people with mental health problems in the workshops are increasing. As a consequence, we will have to adapt our workshops to this change of clientele. This also requires a change in the attitude of our staff there, because these people have different needs to the ones with congenital mental disabilities, don't they? If someone suffers from a congenital mental disability, then they are limited in their mental capacities, and they are always like that, whereas someone who suffers from a mental health problem might have previously been doing a highly qualified job, and now they aren't but in general they will have phases where it is obvious that they have considerable mental capacities and that is, of course, a challenge for the staff.*

— BMAS Civil Servant

Though whether such services were likely to adapt was not seen as likely.

*On the one hand there's the realm of the sheltered workshops in Germany, they are very, very strong, they have an incredibly strong lobby and do not evolve much at all. Basically, a sheltered workshop in Germany does the same thing now that they did 20 years ago.*

— Occupational Therapist

Lack of inclusivity for employees was the criticism of workshops most often raised by participants in this study, creating a separate world for participants to occupy away from mainstream society – particularly for those who both live and work in separate facilities (Klinkhammer et al., 2012). One interviewee was clear, reflecting criticism of sheltered workshops seen in the UK and US and others, that many people with disabilities do not wish to go to sheltered workshops.

*And yes there are many in sheltered workshops too. And there are lots who know about the workshops but refuse to enter them because they feel they are not the right place and feel discriminated and degraded by being stuck together with mentally disabled people. A lot of workshops do not offer special services/departments for people with psychiatric disabilities.*  
— Employment Specialist

Despite increasing discussion of the importance of inclusion for people with disabilities, raised by a number of experts in this study, this may not be applied in sheltered workshops. One expert relayed an anecdote about a training event he attended with representatives from a sheltered workshop, who when asked, could not provide a single example of inclusive practice in their workshop.

*It depends very much on the goals running through a service. What is their motivation – to be inclusive or not? This could be in a social firm as well a sheltered workshop.*  
— Employment Specialist

Despite these concerns, it was clear that experts felt there was a place for sheltered workshops in the German VR system. Though acknowledging that ‘traditional’ vocational rehabilitation such as sheltered workshops are less effective than IPS and supported employment models in return to open employment, research indicates that sheltered workshops are more effective than no vocational rehabilitation in terms of employment outcomes, as well as well-being and functioning (Watzke et al., 2009).

Expert participants suggested that workshops were valuable for those with more severe symptoms and those seen as a significant distance from the open labour market.

*A certain number of patients with schizophrenia will certainly need a place in a sheltered workshop.*  
— Employment Specialist

*And then there are the really severe cases, where you would have to say that these are people who cannot work in the mainstream labour market, because they have difficulties with their colleagues, their boss, and well, because they aren't able to do certain things. It is for people like that that we have the sheltered workshops.*  
— BMAS Civil Servant

As discussed earlier, the structure provided by sheltered workshops was seen by experts as highly valuable.

*They [sheltered workshops] do try to improve these people's resources and just the structure alone gives people stability. So there are different shades here.*  
— Employer, Social Firm

*Also, it must be said that there are likely to be some clients, who need more structured activity, and for whom a pure supported employment project, with them having been placed*

*in a job and then being seen by community mental health staff and the support employment worker, may not be the right kind of service.*

— Psychiatrist/Academic

Whether sheltered employment was seen as valuable by those who participated in them was not investigated in this study – no lived experience participants described having worked in a sheltered workshop. However, two experts made comments in this regard that are worth considering.

One suggested that in his experience working in a Social Firm, some participants preferred the idea of more sheltered working, due to concerns about the pressure of an open employment environment, or wishing to work alongside those with similar health conditions.

*All the people we employ [in the social firm] are in usual work surroundings. But this might not be of use for everybody, there are people who say for themselves they need sheltered workshops, they don't want to be in usual employment, they want the special world with colleagues that understand me, have the same condition.*

— Employment Specialist

In a more extreme example, another participant with caring responsibility reported that the severity of the condition experienced by her brother had left him unable even to work in a sheltered workshop.

*He would have to have someone sitting next to him to see that he sticks with it, I think that would even be difficult in a sheltered workshop.*

— Carer

This emphasises the range of symptoms and symptom severity associated with schizophrenia, and the need to reflect on individual needs and desired outcomes when making decisions about support provision. It is about having a choice from a spectrum of options.

*A different group of people, and those people should be the more severely ill, can benefit from sheltered workshops.... In sum, it depends on the type of intervention which group of patients will benefit from it. The patients who benefit are the ones who match the access criteria most closely.*

— Occupational Therapist

Throughout expert interviews there was some concern that people were led towards sheltered workshops when other levels of employment support may have been more appropriate for their needs. In part this might have been due to the strength, size and therefore higher awareness of sheltered workshops as opposed to other VR services.

The strength and the prominence of sheltered workshops is underlined by legislation (currently under review) which maintains workshops as the appropriate support for those



with mental health conditions.

*Legislation at the moment is such that essentially the only option for people with mental disabilities is the workshops. Everything else is pretty much excluded, because the term “sheltered workshop” is the one used in the legal texts.*

— BMAS Civil Servant

Even among expert participants there was low awareness of the range of employment support available for someone with schizophrenia, including supported employment – which might be seen as filling the space between open employment and sheltered workshops. References were made to people being referred to sheltered workshops due to lack of alternatives, or due to a perception that sheltered workshops are the only appropriate option for someone with schizophrenia.

*Well, as far as healthcare policy is concerned, there needs to be more sheltered workplaces, or there needs to be more flexibility within the workplace, so for example that people can work part-time if they cannot manage full-time anymore.*

— Psychiatrist

*We still need sheltered workshops and I think we might need a third option... Germany suffers from a bit of a dichotomy in the kind of work that is offered. On the one hand there is the regular labour market with competitive work and on the other, there are sheltered workshops and there is nothing in between. We need another type of work opportunity in between, one that has a little less support than sheltered workshops.*

— Occupational Therapist

Though there are convincing arguments for the maintenance of sheltered workshops as a rehabilitation option for people with schizophrenia, the dominance of this option in Germany appears to be problematic. The lack of opportunities for people to progress out of sheltered workshops once they are in them only heightens this concern.

#### **4.3.4.2 The alternative of social firms (*Integrationsfirmen*)**

Social firms, known in Germany as *Integrationsfirmen* or *Integrationsprojekte*, provide alternative employment opportunities for people with severe mental illness – between 25 and 50 per cent of social firm employees are severely disabled. Social firms are either organisations that operate in the open labour market (*Integrationsunternehmen*), or they may be specific social firm departments within companies that operate in the open labour market (*Integrationsabteilungen*).

There are around 600 social firms operating in Germany<sup>37</sup>, employing over 10,000 people (2012 figures) with severe disabilities – 19.4 per cent of whom had a mental health condition (BIH, 2014). In contrast to sheltered workshops, social firm employees operate on a day to day basis like anyone in a usual job in the open market. The businesses are competitive, and wages reflective of those in the open market – one expert told us that the minimum

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<sup>37</sup> <http://www.bag-integrationsfirmen.de/das-netzwerk-sozialer-unternehmen/>

wage in the social firm he worked with was €8/hour, compared with €2/€3 in a sheltered workshop. Disabled employee wages are subsidised to account for any reduced productivity through funds from the disability quota-levy (see 4.2.1.1), collected from employers and distributed through the Integration Office.

An example social firm is provided in case study 1 (page 93).

Like sheltered workshops, social firms in Germany are supported by a strong legal framework, and a Federal Working Group (BAG-IF).

*The social firm model is quite strong in Germany, perhaps slightly weakened, but it's quite strong in this country, in the cities more than in the countryside.*

— Employment Specialist

As with other VR services in this study (aside from the sheltered workshops) it was identified that in recent years people with mental health conditions have decreased as a proportion of the social firm workforce – despite a rise in numbers of social firms and the number of employees overall.

*They still have a number of people with psychiatric disabilities, but the number is not really increasing. The number of social firms is increasing, the number of employees is increasing, but the percentage of people with psychiatric disabilities is decreasing. So people with psychiatric problems are difficult even for the social firm to keep.*

— Employment Specialist

One expert attributed this to market pressures – suggesting that there might need to be greater incentives to employ groups seen as more difficult in social firms. The same concerns around the propensity for the condition to fluctuate and the implications regarding health and insurance and social security provision may be true here also.

Though social firms do provide a form of sheltered or protected employment, these opportunities are much closer to the open labour market than found in sheltered workshops. Jobs are limited and therefore there is a competitive element to finding job, and the businesses themselves operate in the usual labour market.

One social firm in this study was keen to emphasise that they were a competitive business in the open labour market and had to respond to those pressures and operate any other business, and therefore employees were expected to perform.

*I think that's also an important point, that all of our employees here know that we are, I would say, that we are a "normal" business in the general labour market, and we have to compete economically, we cannot survive on subsidies and we cannot rely only on scoring points for our social engagement. That can certainly contribute, but that doesn't create our economic viability and that's pretty much the basic challenge.*

— Employer, Social Firm

Social firms we spoke to raised concerns about the extent of “inclusion” across social firms, similar to concerns around sheltered workshops. It was suggested that the provisions around social firms (and sheltered workshops) in the social code allowed scope for interpretation by providers, leading to the development of quite different social firms, with different priorities and ideology, despite being supported by the legal mechanism and funding. One social firm told us that work is being actively done to promote the idea of “inclusion” and what it means to social firms in their region.

*Because the word “inclusion” is in everyone’s mouth these days, but what it really means, I have to be critical here really, a lot of the time that’s just lip service.*

— Employer, Social Firm

Employees may enter into social firms from various routes, including from sheltered workshops, or as one social firm explained, straight from health services.

*We are working very closely with the hospital, but also with the advice services, and the employees usually come to us for an internship to see how it all works and that usually leads to conversations with the people who look after them as part of their out-patient treatment and that necessarily entails openness and that’s why we know [about their health conditions] pretty much from the outset.*

— Employer, Social Firm

Having a core group of employees with disabilities means that social firms will often also provide additional support for employees – in some ways reflecting supported employment models of ongoing support provision. Job coaches or other support staff may be employed, and the social firms we spoke to maintained good relationships with health services. It was again emphasised however, that though working with health services increases the chances of knowing about the individual’s condition, it was up to the individual employee the extent to which they wished to disclose their health.

As with sheltered workshops, a task of social firms (according to the social code) is to support the transition of employees into the general labour market. Again in reality this rarely happens.

*So the initial idea was to spend two or three years to make these people fit for the regular labour market and then send them back there, that usually doesn’t work. Usually the people who work here, and this is the way almost all social integration organisations have gone, have a long-term perspective with us, that is to say we have employees who have been with us for over 20 years.*

— Employer, Social Firm

This was attributed by experts to individual not wishing to leave the security and the support of the social firm for the open labour market, but also that social firms do not themselves want to lose experienced staff.

There are social firms who are doing excellent work in supporting transitions. Projekt Router (see Case Study 3, page 106) operates under a model which facilitates the transition of individuals between different levels and types of VR services and support, including transition into open employment (with IFD support). Their innovative model involves consolidation of funding from the different agents who fund the different VR services.

#### **Case Study 1 – Social Firm: Irseer Kreis Versand gGmbH**

[Irseer Kreis Versand gGmbH](#) is a social firm mainly for people with mental and psychological disabilities; they are based in the Bavarian region of Kaufbeuren. Established in 1989, it followed the creation in 1982 of Irseer Kreis e.V., an initiative of Irsee citizens for people with mental conditions. Although there are many social firms across Germany, they are the only one in the mail order sector. The firm is competitive in the open market – delivering around 13,000 artistic products and items of therapeutic equipment every year; they have a turnover of nearly three million Euros.

Their main goal is the creation of job opportunities for people with disabilities and they currently employ around 50 people, two thirds of whom have a mental health condition. Most of the positions are regular jobs subject to social insurance and with realistic salaries determined by the existing negotiated guidelines, however, some of the jobs are marginal employment, i.e. €450 job for those receiving reduced earning capacity pension.

There are different ways to get a job in Irseer Kreis: through recommendation/referral from the integration teams at hospitals, via charities and other services – usually coordinated with and by the supported employment service.

The firm also offers vocational training for young people who have difficulty finding a job, working with local training institutions and the regional employment agency – in 2013 there were five people taking part in these activities.

## Chapter 5 Discussion of provision of and access to supported employment vocational rehabilitation in Germany

The Individual Placement and Support (IPS) model of supported employment is the best evidenced vocational rehabilitation method for supporting people with severe mental health conditions, and particularly schizophrenia, to return to and remain in paid employment. Compared to other types of vocational rehabilitation, such support offers improved employment and health outcomes. Even when compared to other effective services in Germany (i.e. RPK), IPS has been found to be substantially cheaper to provide.

The IPS supported employment model is however not delivered in Germany – with legal and funding frameworks in Germany presenting a considerable barrier to the widespread implementation of IPS services. Many elements of the IPS supported employment model can be found in other vocational rehabilitation services, most notably via the *Integrationsfachdienst* (IFD) integration service, and the *Berufstrainingzentrum* (BTZ) vocational training centres. Each come with caveats – while IFD tends to focus more on job retention than finding new work, BTZ involves a considerable period of training prior to the work placement, making it much more costly. *Integrationsfirmen* or social firms are also tentatively included as a supported employment-type service. Although such firms are required to employ a high proportion of people with disabilities, this is also true for other German employers (though the ‘duty of employment’ quota is much lower), and although jobs in social firms are not fully competitive, the firms themselves operate in the open labour market and employees are paid representative wages. Social firms also provide a range of support to help employees with disabilities to retain work and to work optimally. We also again note the existence of various small, independent locally run services found across Germany, the role of which for people with schizophrenia we were unfortunately unable to fully explore in this study. Examples of such services are however provided in case studies 2 and 3 (p104 and p106).

Despite some growth in these types of vocational rehabilitation programmes, and a shift away from more institutional provision, commentators speak of a failure to address the basic problems of the vocational rehabilitation system (Waldschmidt et al., 2009). The continuation of segregated and exclusionary strategies (Biermann, 2009 – cited in Waldschmidt et al., 2009) is often highlighted, and in particular the continuing strength of sheltered workshops – too often seen as the default option for people with severe mental health conditions. While the workshops are widely available and strong, the alternatives are considerably less so, with access to these services for people with schizophrenia highly variable across Germany.

Access to good quality vocational rehabilitation services which have participation in the open labour market as their goal is not straightforward. Indeed, the German rehabilitation system

in general is seen as fragmented, complex, bureaucratic and selective (Waldschmidt, 2009), with complex and rigid legal and funding frameworks, exacerbated by differing responsibilities national and regionally.

This research identified multiple barriers to access to support. These include variability between what is available regionally, inconsistency in what different services actually provide, and disconnects in the system – particularly in terms of referral and the barriers generated by legal structures. For people with schizophrenia, many of these barriers to access are amplified, whether due to specific features or symptoms of the condition, or more often, stigmatised attitudes and misconceptions about the implications of schizophrenia as regards ability to work.

This may also reflect a more general shift in attitude towards mental health conditions identified in this study – with both IFD and Social Firms identifying that people with mental health conditions have decreased as a proportion of their service users in recent years. This is in sharp contrast to the situation in sheltered workshops. For social firms this reduction was despite increased awareness of mental health conditions, and an increase generally in the numbers of both social firms and employees.

*People with psychological problems have got a little out of focus over the last few years – they are not so easy to support. People with learning disabilities, intelligence problems, blindness and so on are often easier to support than people with psychological problems. I have been working in this job since 1983, I would say the proportion of people we support with really severe [mental illness] has decreased A LOT in that time. This means of course also people with schizophrenia.*

— Employment Specialist

The following section provides a discussion of access to, availability of, and quality of IFD, BTZ, Social Firms and sheltered work for people with schizophrenia. As discussed above, these are the formally provided services seen as having the most tangible links to employment outcomes. A lack of quality, national data on access and use of such services by people with schizophrenia, and associated employment outcomes is a barrier to providing a thorough quantitative analysis of the role of these services. Some concerns around data on vocational rehabilitation support are outlined below, before going on to discuss the qualitative evidence around use of supported employment-type services by people with schizophrenia in Germany today.

## **5.1 Data on vocational rehabilitation and employment outcomes**

A particular difficulty with providing an analysis of employment support for people with schizophrenia is that the data that is currently available is not sufficient to show the extent to which services are used by people with schizophrenia, regionally or nationally, nor to demonstrate the effectiveness of these services in supporting people with schizophrenia into open employment. Though our research allows a picture to be formed of how these services provide support, it is vital to acknowledge the importance of better data to improve clarity of the relative benefits of a type of service, and to allow the development of evidence-based

arguments to inform policymakers charged with choosing which services to commission and strengthen in order to improve outcomes.

The lack of quality, national (or even regional) data on vocational rehabilitation services in Germany is a barrier to identifying what is and is not working, leaving us unable to provide objective conclusions about the effectiveness of services for people with schizophrenia, or indeed any other service users. Though some national data is available through the Federal Statistical Office (Destatis), it often does not allow identification of specific health conditions, and in many cases data is on those registered as severely disabled – meaning it is not even possible to make a distinction between mental and physical health conditions.

*If you are looking at the labour office numbers, published by the labour office, its even difficult to get the number for people with this official status of being disabled, and among them you can't separate by different disabilities they don't count them. You just have to estimate.*

— Employment Specialist

No data is available on descriptive employment factors for people with disabilities, such as distinction between full and part-time work, or between training placements and paid jobs, the quality of the job, and whether employment is in social firms, sheltered workshops or with the support of an IFD or BTZ, making it difficult to identify what services people with schizophrenia are likely to use, or whether some groups of disabled people benefit more than others (Waldschmidt, 2009).

The 'usual estimation' for employment outcomes for people with health conditions across the German vocational rehabilitation sector, according to one expert participant, was that one third find employment, one third remain in services (including sheltered workshops) and the remaining third are unemployed.

Individual service providers may collect and publish data on their service – for example data on usage and outcomes were available from several BTZ's, either by request or online (e.g. BTZ Hamburg<sup>38</sup> and BTZ Rhein-Neckar<sup>39</sup>). One expert suggested that the federal working group (BAG-BTZ) was planning to provide data across all 24 BTZ on their website. In general however service use data is not widely available, may not be of sufficient quality, and is unlikely to be comparable across services. Indeed, some services do not systematically collect this relevant data, with one IFD suggesting that details of specific health conditions were not routinely recorded.

*I would guess [most have depression], but we don't count the figures*

— Employment Specialist

It was suggested in interviews that the competitive nature of services, which must tender for

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<sup>38</sup> [http://www.dgrw-online.de/files/icf\\_awk\\_3\\_dr\\_ibes.pdf](http://www.dgrw-online.de/files/icf_awk_3_dr_ibes.pdf)

<sup>39</sup> [http://www.btz-rn.de/fileadmin/CONTENT/downloads/PDF/2013/BERICHT\\_Erfolgsbeobachtung\\_2011\\_-\\_Internet.pdf](http://www.btz-rn.de/fileadmin/CONTENT/downloads/PDF/2013/BERICHT_Erfolgsbeobachtung_2011_-_Internet.pdf)



funding (e.g. for the UB funding), provides a disincentive for individual services to make their service usage and outcome data publically available. Different funders collect their own data for their own purpose, and there is no impetus to share it.

*There is a problem as they have different funding. Two main sources of funding are from the labour office and benefits system and they all have their own targets and data and they don't talk.*

— Employment Specialist

This implies that the segregated and competitive funding of different vocational rehabilitation services is a barrier to the collection and sharing of good quality data which might be used to inform policy and improve service provision.

Our research therefore echoes previous research in highlighting the need for good quality evaluations to be conducted on existing vocational rehabilitation programmes to identify their impact on employment, distance from employment and health outcomes for people with schizophrenia, including in comparison to IPS (Watzke et al., 2009). Consideration of cost effectiveness is also valuable, as seen by the comparison of IPS and RPK (Knapp et al., 2013).

## **5.2. Service inconsistency: quality and standards**

Inconsistency in the nature and quality of services is a barrier to individuals being able to access services which support aspirations for open employment. Despite being underlined by the same legal provisions and receiving funding from the same sources, different services (and particularly sheltered workshops) were suggested to differ considerably in their provision, particularly as regards whether the service is 'inclusive'.

*Some have workshops with 40, 60, 100 people in one organisation, in one building, and this is not inclusive in my mind. My measure would be much more 'how inclusive are the services that you offer?' All the people we employ are in usual work surroundings.*

— Employment Specialist, IFD/Social Firm

Similarly, an Occupational Therapist explained that the service provided through their hospital was not necessarily replicated in other hospitals, which might not share their same vision. It was suggested that the same funding might be used for other, less inclusive and less employment focussed services.

*The fact that we have a strong occupational therapy facility in this hospital is our special feature. It could also exist in any other hospital or clinic, but it doesn't, because they might not happen to have an initiative which uses these financial means to do what we do, but they might do more educational programmes or... across all of Germany, there's a whole patchwork of different measures that are actually provided on a local level.*

— Occupational Therapist

Even services which have more rigid structure, such as the IFD, were noted by one expert

as being subject to considerable variation in quality, which might prove a barrier to employment for participants.

*It could be a good IFD or not. Many are not good – not good funding, not good training, or not good people with as long experience as we have here. There are many different conditions that make somewhere a good choice for people with schizophrenia, and with other problems.*

— Employment Specialist

### **5.3 Geographic variation: the role of the Länder**

A number of participants spoke about the geographic variation in service provision and service availability across the country.

*Every region here has a different range [of services], that's a really peculiar thing in Germany, some regions have a lot and others have very little.*

— Occupational Therapist

Being a federal country with powers and responsibilities devolved in many cases to the 16 states (*Länder*), variation between regions is somewhat expected, with patient choice more limited in some regions than others.

*People should have a choice, and in many regions in Germany you don't have a choice, if you are not able to work anymore you have to go to sheltered workshop or not, that's your choice.*

— Employment Specialist

Wealth of a given region and rurality were highlighted as important factors.

*Take Berlin, for example, that's quite a poor "Bundesland" [federal state] and therefore things like sheltered workplaces, psycho-social rehabilitation, sociotherapy, they are much more difficult to pay for than in a wealthier Bundesland. So I do think that much depends on the financial situation of the respective Bundesland.*

— Psychiatrist

The East/West distinction was suggested to still be relevant, with areas in the former East Germany remaining under resourced when compared to the West, with mental healthcare services seen as of a lower standard (Salize et al., 2007).

*We're actually pretty grateful that it only broke out when we moved to the West, so after the reunification, but I don't know what would have happened if he had been in the old system, if he would have got any support at all there.*

— Carer

*It's a long distance from where people live to where these centres are.*

— Psychiatrist/Academic

*In Germany, that depends a lot on where you live. If you live in a rural area, for example, there will be relatively few options to get access to programmes for occupational rehabilitation. If, however, you live in urban area then there will be several things on offer that you can do.*

— Employment Specialist

Reliance on funding via the duty of employment quota-levy was noted as a contributing factor, as areas with fewer large employers (likely rural areas) will have less funding for service provision.

*If you have big companies like we have in [this city] which try to support people with disabilities, then you have more requests to the IFD. If you have many small business, like in rural regions, they don't have to employ people with disabilities. So in the cities IFD have more clients, more pressures, than in rural areas.*

— Employment Specialist

As signalled above, the social code may be interpreted in different ways leading to variation in services, with interests of regional government identified as an influence, for example, in terms of how much focus is given to movement into the open labour market.

*It's the law in Germany, but the different regions... are slightly different in reading the law... They all construct their support system a little differently. We have different support systems all over Germany. You have an IFD service everywhere, but the service is rather different depending which region you are living in. It depends very much on how the government of your region looks at this support, if it's important to them or not.*

— Employment Specialist

It was also suggested that poor coordination of services might lead to confused and inefficient service delivery in certain areas.

*In some regions there is quite an uncoordinated overlap of services, different providers offering the same thing. The crucial point will be to reduce these overlaps and to coordinate all the different services well and make them well known and accessible.*

— Occupational Therapist

## **5.4 Schizophrenia as a barrier to service access**

Having schizophrenia as opposed to a physical health condition or even a different mental health condition was seen by experts as in itself providing a barrier to accessing some vocational rehabilitation services, particularly those more focussed on supported employment. Our research suggests that the perception of schizophrenia as more difficult to manage and as less likely to deliver employment outcomes, joined with an increased awareness of conditions seen as 'easier to manage', has reduced the opportunity for people with schizophrenia to access supported employment. In many cases leading to an assumption that sheltered work is a more appropriate occupation.

Cuts to funding for many vocational rehabilitation services (stemming from the European recession) were identified as falling heavily on groups seen as harder to support, such as those with schizophrenia, who have been increasingly pushed towards sheltered workshops and disability pensions (see section 4.2.2). This reflects findings of previous research that highlighted, for example, that UB funding is often directed at those seen as more able to work in the open labour market, to the exclusion of those with more severe disabilities and higher support needs (Doose, 2012).

Even within mental health employment services, people with schizophrenia were seen as having poorer access. Representatives from both IFD and BTZ services suggested that an increasing demand for vocational rehabilitation services by people with other mental health conditions was a barrier to service access for people with schizophrenia. In particular greater numbers of people experiencing stress, 'burn-out' and depression (often attributed to factors such as the European financial crisis and general increases in work pressure) has meant more people with a stronger work history have been coming to supported employment services.

*Occupational training centres [BTZ], I usually rather send people with depression than those with schizophrenia, because they are easier to reintegrate into work life.*

— Social Worker

Along with this increased "competition" from those with other conditions, another concern is the shift towards supporting people to stay in jobs, and away from helping people to find new jobs (noted specifically in some IFD services). This creates a particularly negative scenario for young people who have limited education and work experience, meaning they are further disadvantaged in the labour market (Waldschmidt, 2009).

*The IFD support and service is for people who still have a good chance on the labour market. So the other people who are jobless, of course including people with schizophrenia, this is reduced and the expectations are not good for the next year. I'm a little bit depressed about it.*

— Employment Specialist

Employers who are already retaining staff due to the various protections against dismissal for people with disabilities, were suggested to be in many cases unwilling to take on new staff with disabilities. In this respect, we might say that schizophrenia is less of a barrier to working in Germany, but it is a barrier for people finding a job, and particularly younger people with a more recent onset.

*If you manage to adapt the jobs to the needs people have... then it is easier to manage. You can keep them in a job much easier than young people who are 20 and really severely sick. Very often you don't get them back into job. And both might have a diagnosis of schizophrenia.*

— Employment Specialist

Lack of vocational rehabilitation support for transitions from school to work for young people with disabilities/health conditions in Germany was highlighted by the European Commission. They particularly note that IFD is not funded to support school leavers (European Commission, 2011). Specific services (largely pre-vocational in nature) do exist which support young people with health conditions/disabilities. For example, the 'Transition from school to work' programme (*Übergang Schule-Beruf* – part of 'Initiative Inklusion'), provides some support for young people with mental health conditions, though the focus is primarily on those with learning disabilities. BBW (*Berufsbildungswerke*) vocational training centres are directed at young people, and users include those with schizophrenia and other mental health conditions<sup>40</sup>. Though desk research identified that BBW often work with IFD, they were not mentioned by experts, even by those working in IFD. The implication here is again perhaps that there is considerable regional variation in how services work together. Irrespective of this, it is difficult to create a clear picture of what is happening and what is available.

It is also worth noting that previous research has highlighted that the requirement for a disability pass to access IFD services is seen by many people with mental health conditions as a barrier to use (Aktion Psychisch Kranke, 2007).

## 5.5 Referral pathways and awareness

Even where a good quality supported employment service exists locally, this study found that often there are not clear routes into such services, with access largely driven by the awareness of local services among individuals and those involved in their care, as well as by personal attitudes of what type of service is most appropriate for a given individual or health condition. It appeared that gaining access to an appropriate vocational rehabilitation programme could be as much a matter of luck as of judgement.

*I knew through people I know that this [supported employment service] exists and, yes, that's why I tried it. And I had already tried a couple of times to find a normal way in and for one reason or another that never worked out.*

— Lived Experience

*So for someone with these problems it's usually good luck if somebody tells him or her that there is an UB-rehabilitation or an integration firm [IFD] or what good support service is available in that special region. There might be someone in a hospital who gives a good hint or there is a doctor who knows and says, or a friend or relative, or whoever.*

— Employment Specialist

There is no centralised or universal advice service to which people with schizophrenia or those involved in their care might go to access advice and guidance on vocational rehabilitation options.

*The problem in the first place is that there is no real service everywhere that a person with*

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<sup>40</sup> <http://www.bagbbw.de/w/files/statistiken/tee-megatrends-2011.pdf>

*psychiatric disabilities can be addressed to for support in keeping or finding a fitting job.*

— Employment Specialist

In this study we sought to identify the most common routes into vocational rehabilitation services to better understand any barriers to access. Vocational rehabilitation service providers were asked how individuals were made aware of and accessed their service. One IFD informed us that their referrals came through four pathways – through social workers involved in discharge, through psychiatrists, through word of mouth, and through employers with whom they have an ongoing relationship (supported by the legal duty to retain workers with disabilities). None of these routes was identified as following a clear pathway, but were all dependent on individuals happening to have heard about the service.

The IFD informed us of their self-promotion activity to increase awareness of their service. This may be through advertising jobs (e.g. in newspapers, job centres, and through word of mouth), but also, as one IFD employee told us, by their going to hospitals and private psychiatrist/psychotherapist offices, and informing them about the service. When the IFD reaches capacity however, such self-promotion of the service will necessarily stop.

*The other thing is they have so many clients in the IFD, we don't want to advertise the service because we always have too many people to support.*

— Employment Specialist

In some cases a good relationship has been built between the IFD and local clinicians (be that through hospitals or private offices), facilitating ongoing referrals. One clinician described the sustained relationship the hospital psychiatric department had with a local employment service, where contact is weekly and considered routine for out-patients and at discharge. Though even in this case, it was suggested that some patients would get missed.

*I expect that quite a few patients who need that type of care are likely to miss it if length of stay is short. So if the duration of in-patient treatment is a fortnight, then the problem of unemployment may not be dealt with sufficiently.*

—Psychiatrist/Academic

As discussed above, attitudes of health professionals also influence such decisions – particularly as they will need to support the application for vocational rehabilitation support. It seemed that this might go both ways however, with the suggestion made during this study that in some cases hospitals might make inappropriate referrals to vocational rehabilitation services.

*I feel that the issue of work cannot be addressed so adequately within the hospital setting, because their focus is, of course, a different one. They deal with very severely ill patients and if one of them get slightly better, the ward staff often think, they can go back to work full-time, and then they arrive here and we have to say, stop, slow down, there's other steps to be taken in-between.*

— Employment Specialist

This may have been an isolated scenario however, as in the above example a vocational service was attached to the hospital. In other facilities, this link might be less clear and the transition to vocational support might be seen as a less normal process than is seen for those with physical conditions.

*With other illnesses, physical illnesses, cancer, there is an automatic kind of, before discharge, an automatic kind of thing whether you want to go to the rehabilitation. And you have to go straight away to a medical rehabilitation service... These are special hospitals but they do see to the vocational side, too. But now comes the BUT, with the psychiatric patients, it seems to have not been automatic, this is what I see as a big problem for the future too.*

— Occupational Therapist

In some cases, referrals to vocational rehabilitation occur as part of the discharge from hospital/in-patient facilities (as part of their discharge report/ongoing care plan), or as part of out-patient services. Again, this was highly variable between facilities. One social firm described their close relationship with their local hospital's Work Integration Team (*Integrationsteam*), the 'I-Team', which is part of the out-patient service. This 'I-Team' assesses the individual's capability and recommends them for employment in the social firm. Another example of integration between health and employment services was arbeit & integration – a BTZ-type service as part of the hospital occupational therapy department (see case study 2).

Social workers often have a role in linking individuals from hospital into vocational rehabilitation services.

*The social workers in the hospital told me that there is this programme or this option and they also advised me to apply for a disability pass and I think both of these were very helpful pieces of advice.*

— Lived Experience

*That's part of my job, that I give information to these people and also that I try to link them up with those services. That we arrange an appointment, that they go there and introduce themselves, that they look at the facilities and that we then fill in the applications together and that they are then guided in steering committees in order to get into the various reintegration support measures.*

— Social Worker

There was again some doubt as to how common it is for social workers provided this type of support. One expert estimated that only around a quarter of social workers might be sufficiently engaged with patient employee to inquire about their work status and refer them to an IFD.

*If you are in a psychiatric clinic you might be lucky that one of the social workers is engaged and says oh you have a job and gets in touch with the IFD, has a transfer meeting, and*



*they'll help you to keep the job or to get into a new perspectives.*

— Employment Specialist

### **Case Study 2 – Vocational rehabilitation: arbeit & integration e.V.**

Arbeit & integration e.V. is an association for people who are unemployed or cannot return to employment because of a mental health condition/disability. Established in the late 1990's, it operates in the area of Düsseldorf. Patients with psychosis make up approximately 20 per cent of the service users (a proportion which has fallen in recent years). By 2012 around 920 people had participated in arbeit & integration rehabilitation, with 70-80 per cent of the participants successfully placed in a new employment.

Arbeit & integration is a local alternative to BTZ and RPK, providing an independent, unique service in the field of vocational rehabilitation and integration. They collaborate with IFD Düsseldorf to provide services within the open labour market. At the same time they link their support into a hospital occupational therapy – collaborating closely with the LVR-Klinikum. Participants undertake a twelve month full-time programme of preparation for employment. Within this, arbeit & integration supports identification and completion of an internship three to four days per week, often in a work area in which the participant was previously employed or in which they have an interest. On their 'day off', participants attend group therapy accompanied by a psychologist, to discuss and reflect on different aspects related to vocational (re)integration, e.g. stress and stress-management, communication, project work, conflict management, etc. Participants are supported by a Job Coach during the rehabilitation process, who accompanies the individual to interviews and supports them in arranging and completing their internship.

Arbeit & integration is funded by the Federal Pension Fund and the Employment Agency. In order to enter arbeit & integration, participants must have completed their medical rehabilitation. They then need an approved rehabilitation application and/or a cost approval from the employment office or the pension insurance funds. They can then be interviewed by arbeit & integration.

The same was true of 'case workers', who (where they exist) also may have a role in providing support to enter vocational rehabilitation programmes.

*There aren't case workers available everywhere, to accompany them [people with schizophrenia]. Case workers are often available from hospitals, but not all the time, so this interface between treatment, medical treatment and rehabilitation, that has to be improved.*

— Employment Specialist

Other pathways into vocational rehabilitation services might include the local job centre/employment offices.

*I was referred by the job centre. I wasn't aware of it before that.*

— Lived Experience

*I was assessed by the job centre, to see if I would be able to manage the retraining at all [at the BTZ]. They said at first, well, maybe it would be better if I don't train as industrial business management assistant, because that could potentially be too challenging.*

— Lived Experience

Given their role in employment service and benefits, this might appear a natural fit. Again however, whether this happens consistently is questionable – with one IFD noting that job advisers at the local employment office were not aware of his IFD. Another expert showed concern about the lack of links between government unemployment support and the health sector.

*The link of the unemployment offices, services aiming at labour market integration of the general population and the mental health sector is insufficient. There is no sufficient inter-agency collaboration, there is no cross talk that corresponds to the size of the problem or the importance of the problem.*

—Psychiatrist/Academic

Community services were also mentioned as having a role.

*So what happens is that they get discharged into community services... but then it's up to those community services to say hey, here is somebody who is young enough, who has had a job, who needs vocational rehabilitation.*

— Occupational Therapist

Carers, friends and family were all also noted as potentially having a role in accessing and identifying services, as were peers workers. Often again this was through word of mouth, with someone happening to know about a particular service.

*I think there are plenty of offers, but you really have to know what could be of benefit to you, that's where experiences of former patients like me can be helpful, too, but I wouldn't say to someone, like following a certain matrix, you have to do this or that. Then you will end up exactly where you want to be.*

— Lived Experience

Though it is clear that there are a number of pathways through which someone might be directed towards appropriate vocational rehabilitation support, none of them is guaranteed, but instead they are reliant on personal interest, personal knowledge, and subjective assessment of ability. As a consequence it is likely that there are many people with schizophrenia (and other conditions) who are not aware of, and therefore are not able to access such services, and as such do not have fitting support. These individuals may be relegated to the sheltered workshops (unpalatable for many people with mental health conditions) due to a lack of alternative opportunities and support.

Referral pathways between the different vocational rehabilitation services were also unclear and found to vary considerably. During this study, examples were found of BTZ and IFD, and IFD and social firms working together, helping people with different needs, or the same people at different times. It was also made clear that such relationships are unlikely to be found across the board.

*We have a rather close cooperation in several fields. Maybe we from the IFD can say to*

*people go to BTZ, its best for you and your situation. We can help them with the application, waiting time, and problems like that. And after they have trained in BTZ and found a new way to work, the IFD can support them to keep their job and to further adapt to their situation, and if they have new problems we can accompany them. But this is the situation in [this region], and it's not really representative all over Germany I would say.*

— Employment Specialist

A conversation with a different IFD found them unaware of what a BTZ was – though it is noted there was not one available in their locality. This raises concerns about the variability in knowledge about vocational rehabilitation options among those working in health and employment sectors, and how this might affect someone with schizophrenia's access to appropriate services.

The apparent difficulty transitioning out of services, particularly sheltered workshops, is concerning given the goal of achieving competitive employment in the general labour market. A lack of movement and flexibility within the systems, driven by the funding structures, was a clear concern of some expert participants. The consequence being that once placed in service there is little support for people to find their way out, and therefore they may become trapped in the first vocational offer made to them.

Case Study 3 describes an innovative model which supports transitions between different types of vocational rehabilitation. What is fundamental in this model is the promotion of choice, and support for transition usually blocked by lack of information or legal provision.

### **Case Study 3: Projekt Füngeling Router**

Projekt Router is a supported placement and qualification project for people with severe disabilities (including mental health conditions) run by the Füngeling Router gGmbH, and operating in Cologne. Projekt Router might be considered a unique integration model in Germany – providing several different vocational rehabilitation options under one roof. This is done through merging existing legal instruments for the integration of people with disabilities according to the individual's level of productivity and support needed at a given stage. Funding instruments include social security, the duty of employment quota-levy, the labour office, benefits insurance, and various other government programmes. The complexity of merging funding means that it is a rare organisation – thought to occur in only a few other sites in Germany.

The general principle is employment in regular firms supported by professional job coaches. Clients of Projekt Router may be receiving any one of the following provisions – apprenticeship/training, supported employment (UB SGBIX 38a), WfbM status supported work, transitional vocational qualifications (*Übergangsqualifizierung*), direct employment (through the social firm element), temporary employment, apprenticeships and internships, job matching, psychosocial and workplace integration support, counselling and advice and job matching.

Projekt Router successfully supports people with disabilities as (prospective) employees, working with private company partners in what Eurofound defines as a “win-win situation”<sup>44</sup>. The final goal is always, the permanent hiring of the employee by the company and/or the future transfer of all employer responsibilities to the company, as well as a long-term placement of the individual with disabilities in their workplace.

## 5.6 Attitudes and judgements

Stigmatised attitudes about people with schizophrenia, their ability to work, how work will affect them, and consequently what vocational rehabilitation services are appropriate also present a barrier to accessing appropriate services.

In many cases individuals with schizophrenia will receive support or advice on which services to apply for, including vocational rehabilitation. Whoever provides this can have considerable influence on which services are accessed. Their judgement on what is appropriate will likely have been influenced by a range of factors, including their perception of schizophrenia and how it influences someone's abilities may be critical, as well as their previous experience of the funding bodies.

*Well, our patients, because they are often really severely ill, I would suggest the reintegration support measures [Eingliederungshilfemaßnahmen], that's the ones I would root for. Day care centres, minor additional earnings, voluntary work may also be a possibility, but many people find that difficult, yes, that's the main ones I think, and maybe also the sheltered workshops.*

— Social Worker

As mentioned social workers (particularly those working in hospital psychiatric facilities), and to a lesser extent *Betreuers*, were identified as having a role in supporting individuals to apply to vocational rehabilitation services and other social support. In interviews, both the social worker and the *Betreuer* stated preferences for types of services to which people with schizophrenia might be referred, based on their experience. In both cases this was sheltered work. It is noted that both are in positions where they are likely to be in contact with individuals at early stages of recovery.

*I'm mostly in favour of sheltered work... Yes, yes. Because the people there know what's going on and in a normal working environment, I mean in a competitive working environment, they can't be considerate of that, or rather they just aren't considerate of it.*

— *Betreuer*

Concerns about the influence of individual attitudes were well demonstrated by the very different views found about the suitability of BTZ for people with schizophrenia. One social worker was clear that in her view BTZ was unlikely to be appropriate, noting in particular that 15 hours a week was too much for someone with schizophrenia, and that the service was more suited to people with depression. In stark contrast, a BTZ who participated in this research stated that people with schizophrenia had the best outcomes of their service. Therefore, there is reason to believe that people are not being referred to services which might help them due to (in some cases) unsubstantiated views about capacity.

Poor awareness of the outcomes of individuals referred to different services after leaving the hospital might also limit the opportunity for a 'referrer' to gauge whether they're making

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<sup>41</sup> <https://eurofound.europa.eu/observatories/eurwork/case-studies/egs/fngeling-router-job-creation-project-germany>

appropriate decisions or to explore a wider range of services.

*I can't judge that, because I don't know what happens to them after they are discharged from here, which means I put in the applications and then unfortunately I don't get to know the outcome.*

— Social Worker

## 5.7 The role of funding bodies

Access to vocational rehabilitation services requires an application to be made to and approved by the relevant funding body for that particular service. This presents a further administrative barrier to accessing appropriate support. While health services are funded through health insurance and controlled by the “*Medizinischer Dienst der Krankenkasse*” (Medical Review Board of the Statutory Health Insurance Funds), vocational rehabilitation services may come from a number of (or combination of) funders, for example the Pension Fund (*Rentenversicherung*), the Employment Agency and job centre, and the Integration Office (*Integrationsamt*). Applications will be made to a different organisation depending on which service is being sought, and they will assess it with their own specialists. This is on top of the assessment conducted by the healthcare professional involved in making the application (often a general practitioner, psychologist or psychiatrist). The assessment includes determining the number of hours an individual will be able to work – important for deciding which vocational rehabilitation service is appropriate, as well as eligibility for early retirement pensions.

[Interviewer:] *Are your doctors and medical team supportive about you finding work?*

[Participant:] *Not directly, well, they do set out recommendations about how much I can work, but that was done in hospital and the Employment Agency has checked that*

— Lived Experience

Ultimately, even where there are quality services available locally, and clinicians and support workers know of them, advise people to go for them, and/or provide support for an application to them, the placement decision rests with the funding body for that service.

*The patients themselves can of course state their preferences and that's why I always try to inform the patients of all the options – all the options that I know. And I find this occupational training centre [BTZ], that's one of the options, I find that a very good facility and I like sending people there because they assess on a very individual basis what suits different people and try to find something in that area. But at the end of the day it's the decision of the paying authorities.*

— Social Worker

The sheer complexity of the systems for accessing vocational rehabilitation has been highlighted as problematic from the perspective of the individual and service providers who have to navigate their way through.

*I've already mentioned in the beginning how complicated the whole thing is with Pension*

*Fund on State level and Länder level and Employment Agency, that might be difficult to understand for you [the interviewer] – it is for us as well! And it is especially difficult for people with schizophrenia.*

— Employment Specialist

The bureaucracy associated with these processes is seen as problematic, making the system complex and hindering access to support. Previous research has noted the propensity for people to drop out during the course of the application process (Waldschmidt et al., 2009). This is likely exacerbated by the variable availability of social workers and case managers who might otherwise provide support and advice on the application process.

*And that's a problem, you see. You have to fill in many applications, you have to attend many appointments with administrators at the funding agencies and that often takes months or even a year. So even if you are in hospital and you're stable again and you want to go back to work, so much time is lost and it is very complicated to put in all these applications.*

— Employment Specialist

*Well, they make it very complicated and there's the option of applying for occupational rehabilitation with more than one institution, but they all insist on doing their own thing, and they all want assessments by their own specialists, despite the patients being in hospital here, so I find that a very complicated and drawn-out process until these people finally get into the occupational rehabilitation where they belong.*

— Social Worker

There was also some wariness about the quality of the decisions made by the funding bodies. A social worker, heavily involved in supporting transitions from hospital to vocational rehabilitation, had formed a negative impression of their decision making, and whether decisions were made in the best interests of the patients – fearing the onus was on reducing the unemployment figures rather than seeking the best outcomes.

*Well, to put it bluntly, from my experience, from what I've heard, they just decide to put these people in any kind of programme, just so they disappear from their statistics, for example as "looking for work". And if there's a free space in "How to apply for a job successfully?" then they all get put into that course.*

— Social Worker

## **5.8 Relationship between health and vocational rehabilitation systems**

The role of health professionals outside of vocational rehabilitation services was raised numerous times in this study, in particular in the nature of the treatment they provide, attitudes towards work for patients with schizophrenia, and their assessment of which vocational rehabilitation service should be applied for. As discussed in this section, the way that vocational rehabilitation and medical treatment and rehabilitation services interact and the strength of their relationship is also very important in ensuring people get access to appropriate vocational rehabilitation.



As identified in the IPS model, in which co-location of health and vocational services is highlighted as best practice in terms of achieving employment outcomes, health and vocational services need to work together and support each other to achieve the best outcomes for the individual. Though co-location may not be feasible in Germany, as we have seen above there are good examples of vocational rehabilitation services working well with clinicians in order to facilitate referrals. There were also good examples of good ongoing relationships between services.

Many vocational rehabilitation services have some professional psychological support within their service – either working as an employment specialist (*Integrationsberater/in*) or as an attached psychologist. There may also be external links – one BTZ described their relationship with external office-based psychiatrists, which allowed knowledge on an individual patient (subject to permission) to be shared.

*We work together with them, so we coordinate, we speak on the phone or we receive their reports, if the participant agrees, so that we know what diagnosis exactly was made and the course of the illness. And usually the doctors want to know our reports and our experiences too and there's usually a very good cooperation with the psychiatrists, but also with psychotherapists outside the occupational training centre, so we have a good network and we work closely together, if the participant is happy for that.*

— Employment Specialist

Such relationships varied considerably depending on individual services, with little in place to manage or support them. In our study, poor linkages between mental health treatment and vocational rehabilitation services and an overall lack of structure and collaboration in this regard were highlighted as creating barriers to employment.

*There is a multitude of work related services, some with a focus on people with severe mental illness, but integration is not sufficient. I think we are moving in the right direction, but this movement is very modest and slow.*

— Psychiatrist/Academic

The rigidity of legal and funding provisions, that prevent a more structured and consistent working relationship between medical and vocational rehabilitation services, were identified as presenting other problems in terms of access to appropriate vocational rehabilitation services. Many of the issues around funding and legal provisions discussed through this report stem from the Hartz IV social security reforms, which led to the separation of legal provision for unemployed people and unemployed people with chronic conditions and disabilities, meaning job agencies had to consider two different books of the social code (Book 2: Basic security for job seekers and Book 9: Rehabilitation and Participation of Disabled People) (Waldschmidt et al., 2009). Medical and vocational rehabilitation services may also be provided through the health insurance (Book 5) and the pensions fund (Book 6) – all legally separate with responsibilities rigidly defined.

In reality, this separation leads to many people falling in the gaps between services and



jurisdiction. For example, where someone is in a vocational rehabilitation service funded by the pension fund, but they fall ill during this programme and require medical treatment or rehabilitation, which funder is then responsible for them? Their health needs push them into the realm of health insurance, but health insurers do not provide vocational rehabilitation.

*There need to be clearly defined responsibilities [for funding agencies]. It is unacceptable... we have several funding agencies in Germany, at least the three big ones, health insurance, unemployment insurance, pension funds. Those three have to come to an agreement. They basically have to forge one unified rehabilitation system, so that we have clear and immediate answers as to who is responsible – that is, paying – for what.*

— Occupational Therapist

This separation can mean an individual must leave vocational rehabilitation to enter the medical treatment and rehabilitation, and therefore will have to go back to the end of the queue for vocational rehabilitation after the acute treatment phase is over (Watzke et al., 2009) sometimes involving a considerable waiting period (estimated by one expert at six months for BTZ).

## 5.9 Time-limited provision

The way individual services are funded provides a further set of concerns. Supported employment vocational rehabilitation services, particularly IFD, are only provided on short-term contracts. Experts felt that such a scenario was severely limiting the ability of these options to become embedded, and ensured supported employment programmes would remain weak compared to sheltered workshops.

*This makes the programmes very, very weak and they can't achieve much. That's the complete opposite of these extremely strong sheltered workshops, which exist continuously, which are set in concrete. Germany really needs to find a third alternative here.*

— Occupational Therapist

Organisations tender for funding to provide supported employment services. While IFD generally have three years of funding, one expert referred to programmes with only a single year funding. The tendered, short-term funding model was criticised in interviews as placing such services at a considerable disadvantage compared to sheltered workshops, who receive stable and ongoing funding, for which they have to do little to achieve.

*They [sheltered workshops] don't develop much at all, they are set in concrete, a bit like during the socialist era, perhaps. And on the other hand there are the programmes offered by the Employment Agency, and they are put out tender, literally, just as if you build a house and put the installation of the windows out to tender. So the providers have to bid for it. The situation is the exact opposite... This makes the [supported employment] programmes very, very weak and they can't achieve much.*

— Occupational Therapist

Short-term tendering was suggested to provide a disincentive to staff who could only be

offered short contracts, as well as being problematic in terms of what can be achieved in such a constrained time period. A particular concern was the difficulty short-term funding presented when building and maintaining relationships with employers. As defined in the IPS model, the best outcomes come when employers also received ongoing support from an employment specialist, though this is not possible if the provider loses the service when re-tendering. One expert reinforced this point:

*They [employers] would say if you have a stable service that I can rely on, that I can call, that will come and help me, that is very much what I need...If someone gets sick on the job and I don't know what to do about them, this is the most important this for me. That's what I heard all over the place.... They [job coaches] have to give them [employers] safety – I'm with you if you have problems you can call me and I'm coming and helping, you, and this must be a stable and safe system.*

— Employment Specialist

The ill-effects of short-term funding are consolidated when acknowledging the European Commission's concerns that there may be a tendency to choose cost over quality in tendering decisions (European Commission, 2011).

## **5.10 Early intervention in employment support**

Early intervention has been shown to be important, in terms of clinical, social, and functional recovery. This is also true in terms of vocational rehabilitation.

Experts interviewed did not explicitly mention the vocational rehabilitation programmes available for young people with schizophrenia in Germany, though several discussed the difficulties for young people with schizophrenia in entering the labour market. Participants working across health, social work and vocational rehabilitation suggested that more attention should be given to providing rehabilitation for younger people with psychosis.

*People who are older... they have already had all the services. I don't really have to do anything with them, they are already linked up very well. It's mostly the younger people, let's say the 25-35 year olds, that really require my help.*

— Social Worker

*If you have it when you're young, at the end of school education, 18. Then if it's really severe at this time, you don't get into the labour market at all.*

— Employment Specialist

Often schizophrenia symptoms come at a critical age for transitioning to independent living, and for education and employment (Rinaldi et al., 2004). Integration of IPS with early intervention services is seen as a way of preventing young people from being excluded in these areas. A recent UK trial, wherein a model of IPS which included education was integrated into Early Intervention in Psychosis teams, showed excellent outcomes over a 24 month period particularly in terms of moving people into open employment (Rinaldi, Perkins, McNeil, Hickman, & Singh, 2010).

## 5.11 Key messages

We found a mixed picture of the German vocational rehabilitation system. On one hand there are many funded services available and supported through the social code, some elements of which reflect evidence-based service provision and appear to lead to improved employment outcomes for people with schizophrenia. On the other hand, there are numerous issues with accessing these services – some of which are relevant to many health conditions, while others specifically to schizophrenia. The variation in quality, consistency and funding for services, poor clarity about how to enter them, and difficulties within the process of applying for services, means that in many cases, gaining access to a vocational rehabilitation service is less about what someone needs, but more about who you know and where you live.

A considerable barrier to improving access to vocational rehabilitation services for people with schizophrenia is the paucity of data showing the usage and employment outcomes for people with schizophrenia entering various services. If people do not know they are effective services, then they will not be made available for people with schizophrenia.

A number of themes have been drawn out for consideration. Firstly the need for greater **choice** to allow people to access the services which best suit their condition, their abilities and their desires, regardless of where they live. Secondly the need for increasing **standardisation**, so people know what a given service is *actually* providing and what outcome they are seeking (e.g. inclusive employment). Lastly, the need to improve the **linking of services**, in particular developing clearer and faster pathways that support referrals into vocational rehabilitation services and transitions between them, and enhance the capacity for vocational rehabilitation services to work together in a way that reflects best practice, and to work with medical treatment and rehabilitation services.

Many of the current difficulties are symptoms of the legal segregation of medical treatment, rehabilitation and vocational rehabilitation systems, and the different funders – making it difficult to develop effective services across health and labour systems, and allowing gaps to form between what the different funders provide. The static nature of the vocational rehabilitation system also means that though a lot of good things exist, people have a difficult time moving into them.

*There needs to be more movement in the system, it's too static... there is quite a lot being offered but pathways are too cumbersome, too slow and the system is not responsive to the needs of people with severe mental illness.*

— Psychiatrist/Academic

## Chapter 6 Conclusions and Calls to Action

### 6.1 Evidence and action

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 extensively tested interventions to support people with schizophrenia into sustainable, competitive employment, why have we made no appreciable progress in employment rates?
2. If we can agree that the status quo is unacceptable but not inevitable, what are the key areas where reform would improve outcomes?
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 aspiring to them?

Though evidence-based support and interventions which enhance recovery prospects and support people with health conditions and disabilities into sustainable, competitive employment, are available and cemented in the social code, too often these pathways are not the ones taken when it comes to people with schizophrenia. Barriers to this are found in the health system, the vocational rehabilitation system and in labour market activation policies, and are underscored by people's attitudes to schizophrenia and lack of consensus on what appropriate labour market outcomes are for those with the condition. Too many people with schizophrenia, and particularly young people, are passed over by the labour market without having been given the chance to participate, and consequently find themselves excluded completely.

A key criticism of the current system of vocational rehabilitation is the complexity – the confusion, delays and restrictions to access this creates is a considerable barrier to appropriate, evidence-based support to help people with schizophrenia enter and retain gainful employment. In addition, the condition schizophrenia is seen as relatively insecure from an insurance liability perspective, further reducing the range of support seen as appropriate.

In light of this research, a few core areas for change have been identified where new energy should be directed at the goal of improving outcomes in the open labour market for people with schizophrenia. Some specific recommendations/examples are provided where the research identified them.

## 6.2 Calls to action

### *Condition-specific employment and vocational rehabilitation data on a national level*

In order to allow a clearer assessment of the current picture for people with schizophrenia (or severe mental health conditions more generally) with respect to employment, there needs to be **improved data collection and data sharing of employment outcomes and use of sheltered, pre-vocational and supported employment services**. This is necessary across organisations and funding bodies, on a national and/or regional basis. This would not only allow a better estimation of the successes and failures of the current system, but would also provide data through which change in outcomes can be measured in light of policy developments.

### *Funding barriers and linking health and vocational services*

The multipartite system of insurance through which medical treatment, rehabilitation and vocational rehabilitation services are funded, provides a formidable barrier to the development of more holistic models of working across these areas. This has implications for the collection and sharing of data, as discussed above, but also more generally in providing clear pathways for referral and transition between services, and in the provision of complementary support across actors with the aim of reaching shared outcomes, i.e. the employment of people with health conditions.

Having to effectively leave the vocational rehabilitation system in order to access treatment services in the event of relapse, can be a damaging consequence of the funding system. This not only causes considerable delay to accessing appropriate support, but in some cases forms a barrier to vocational rehabilitation services altogether. **Entry and exit into systems needs to be timely and more flexible** to allow for overlap to account for such scenarios, particularly with conditions such as schizophrenia where relapse is not uncommon.

The current application processes for different vocational rehabilitation funders and services have been highlighted as barriers to access. The administrative burden, the waiting times to access some services (lasting several months in some cases) and the emotional strain this may cause those waiting for an outcome, can lead people to seek the 'safest' option – most often the sheltered workshops, the most well known and widely available service. **A more centralised assessment and application process, rather than direct application to specific funders, might allow greater flexibility and choice in service access**. This would likely work best at a regional level, given the considerable differences often found between regional service provision – perhaps led by strengthened regional working groups (the existence of whom is noted in the SGB IX). Such working groups should actively engage with people with disabilities/health conditions, to ensure that new models are developed taking account of the need of service users.

Insurer funding is also a fundamental barrier to the implementation of the evidenced-based IPS supported employment model. This requires **vocational and health services to be co-**

**located and have a strong working relationship**, moving together with the individual towards their desired recovery outcomes. Recent success in Switzerland in introducing IPS may serve as a valuable model for how this might be achieved in Germany.

Links between services do exist – hospital work integration teams and services such as arbeit & integration (see Case Study 2, page 104) show how **models can be developed which facilitate improved collaboration between medical treatment and vocational rehabilitation sectors**. Lessons from such services include giving occupational therapists, already a prominent part of the German rehabilitation system, or hospital social workers, who are usually involved in discharge process, more specific roles in facilitating linkages between medical and vocational services. This might include the discussion of employment aspirations with patients, provision of information on the range of local opportunities available, and ensuring patients are linked in with the relevant services as part of the hospital discharge process.

**Improved joint working and communication** may also address the scenario identified within the health system wherein people are being discharged prematurely to vocational rehabilitation services, when they may actually require a longer period of treatment. **Greater shared decision making between the different players, including the individual patient**, might prevent this from happening. **Introducing flexibilities into the system which allow quicker passage and overlap between different services**, so that some rehabilitation support can be delivered without an individual being discharged from treatment explicitly into rehabilitation services, may be worth considering.

Project Router (see case study 3, page 106) is a rare model which enables different types of vocational rehabilitation funding to be brought together to provide a service focussed on individual needs, supporting their transition and progression into services offering different levels and types of support. The complexity of developing such a service was identified by the service providers as a barrier to its replication. Such barriers need to be addressed.

Unemployment offices/Job Centres were rarely mentioned in this study as a source for accessing information and support for vocational rehabilitation services. This is an area where their influence might be expanded. One suggestion might be **greater collaboration between local unemployment offices and community mental health treatment and rehabilitation services to support people with mental health conditions into work**. A designated mental health support officer role within Job Centres might be created to allow greater focus on this. This role could liaise with local mental health workers, and together they would support employment outcomes for in-patients, out-patients and people in the community, linking in with GPs and secondary mental health services.

### ***Achieving a better balance between sheltered and supported employment***

The considerable influence of the sheltered workshop model, in the social code as well as in the public's minds, represents a barrier to the development of more inclusive, cheaper services, with better evidence of positive and sustained employment outcomes in the open

labour market (such as the IFD and BTZ services). **The dominance of sheltered workshops in vocational rehabilitation options needs to be addressed.**

The perception of schizophrenia as a variable and unpredictable condition makes it appear an insurance risk for funders – making the consistency and security of a WfbM appear a ‘safe’ option. There also therefore needs to be **an active effort to strengthen the alternative supported employment sector**, which is currently constrained by a shortage in funding and the short-term nature of that funding. This reduces the providers’ ability to plan, improve and embed services, to provide services to enough people, and in turn employer and service user confidence in their services is reduced. In addressing these issues, awareness of the evidence-base, the credibility, and the existence of the supported employment alternatives will be increased.

The strengthening of supported employment alternatives should also improve geographical availability of such services, making sure that they are accessible across Germany, outside of the urban centres. Ensuring that services are widely available might require there to be less reliance on the duty of employment quota-levy as the primary source of funding for some services, or different models of redistribution of such funds.

In order to improve general knowledge about the range of services and support available across different funders there may be benefit in developing a unified advice service – **a regional ‘one stop shop’ for advice and information on the range of relevant health and vocational support in that region, both for job seekers and those concerned about retaining their jobs.** This could be an online service, but with phone advice available, or make use of existing structures (such as those provided through welfare or health services). This should also include legal information on disability employment activation policies, for individuals and employers. This should be accessible and appropriate for individuals with and without a disability pass.

Both sheltered and supported employment services might also benefit from more **clearly articulated service aims and the introduction of quality standards to support those aims being met.** For sheltered employment, this might provide a few underlining guidelines for good services – emphasising that inclusion should be a primary focus and that there should be a minimum salary which offers dignity to the employee (in the UK employees of ‘supported businesses’ receive at least the National Minimum Wage).

Greater emphasis should be placed on **the role of sheltered workshops in supporting people into open employment** (as outlined in the social code), as current outcomes are disappointingly low. Reform of this sector in the UK may serve as a valuable model – where social firms are increasingly seen as a pathway out of sheltered workshops, with many workshops being developed into social firms.

The strength of the supported employment sector is very important in securing successful transitions out of sheltered work, as many people will still require ongoing support to move into, and remain in, the open labour market. **The Budget for Work** (*Budget für Arbeit*)



programme, which provides support for employers employing someone with a disability, could be **better targeted at those with the highest levels of exclusion from the usual labour market** (including people with schizophrenia). It is suggested however, that with a range of support in place, such as that provided by the IFD, these incentives or compensation for employment would not be necessary in the longer term.

### ***Work as an outcome for people with schizophrenia***

Achieving a better balance between sheltered and supported employment also requires a cultural shift. There needs to be **greater recognition that employment in the open labour market is a desirable, achievable and therapeutically beneficial goal for many people with schizophrenia**. This message needs to be disseminated across the health and social care sector, as well as to individuals with schizophrenia and carers. This is vital if employment outcomes are to be reflected in referral decisions, as well as in treatment decisions. With the strengthening of alternative vocational rehabilitation services referred to above, and improved relationships between health and vocational sectors, clearer pathways between services should develop which will ensure that more people are put on the most suitable pathway for them.

This will not come naturally and will likely require some active intervention to ensure that the message is getting across, possibly through **training and improved dissemination of the evidence-base** for alternative models (including pilots and demonstration sites). It is part of a **broader shift in thinking around what individuals' aspirations around recovery actually are, which should be reflected in treatment decisions**. The focus must be put on promoting and ensuring access to appropriate interventions, particularly psychotherapeutic, in a timely fashion. In some cases this may require some incentive to encourage clinicians to take on patients who they might view as more difficult to help (as suggested for people with schizophrenia).

**In the current climate it is young people with schizophrenia, with limited work experience or education, who are being failed the most by the system.** Much of the available support is focussed on job retention or on returning to previously held jobs and areas of previous employment. Employment quotas for the severely disabled and protection against dismissal mean that people stay in their jobs, without new opportunities becoming available for younger, less experienced people. Joined with poor access to early intervention treatment and complexities around rehabilitation, many are becoming locked out of the labour market and into disability pensions at a young age. This needs to be addressed urgently if the life-course impact of schizophrenia on young people is to be minimised. Though programmes which seek to support young people with disabilities in their transitions from education to employment do exist (e.g. *Übergang Schule-Beruf*, part of 'Initiative Inklusion'), again these are often provided for people with learning disabilities, rather than those with mental health conditions.

It is also clear that **other health conditions, including some mental health conditions, are given greater priority over schizophrenia** in both treatment and rehabilitation

services. This too needs to be addressed, as people with schizophrenia are being pushed out of services where cuts have to be made in favour of those with more 'common', easier to manage, and politically prioritised conditions, such as depression and burn-out.

One suggestion was to **allow greater flexibility in the incentive payments given to employers of social firms taking on employees with disabilities**, so as to provide greater incentives for people taking on more excluded groups such as people with schizophrenia, and to encourage and incentivise integration opportunities.

### ***Supporting employers***

Employers need to know that there is high quality sustained support available to them should they employ or retain an employee with schizophrenia. Support is available through the IFD (though funding restrictions hinder this significantly), as well as through BEM, though awareness of both are low. In some cases there is too great a focus on employers employing people because they have to (due to the duty of employment quota-levy and protections against dismissal), more than through the recognition of an individual's skills and abilities as an employee. **Improving employer awareness of the support that is available, improving the sustainability of support, and availability of support will improve employer confidence in employing people with such conditions.**

A shift in thinking towards **focussing on what an individual can do, as opposed to what they can't**, will promote a different way of thinking about employment of people with health conditions – enabling employers to focus on the benefits of employing someone, irrespective of their health condition.

## **6.3 Sustaining success and aiming higher**

In the current labour market, for many people with chronic or fluctuating health conditions, keeping or getting a job is regarded as an achievement in itself. But evidence indicates that the prevalence of long-term health problems within the working age population is set to increase over the next 20 years. 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 ensuring people are occupied, and instead strive to move people into gainful employment, supporting individuals' movement towards their recovery goals, while allowing them to contribute to the national economy. An inclusive labour market is needed, populated with inclusive workplaces, supported by a healthcare and welfare system which prioritises good quality work as a clinical outcome. It is recognised that there is some distance to travel before this stage is reached, 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 type of people interviewed and their job roles.

### **Employment specialists**

Several of the participants we interviewed were assisted in their job search by an employment worker. The employment workers we questioned came from different organisations, providing IFD, social firm and BTZ-type services. All of whom were focussed on providing support to people with mental health conditions to remain in their current job or find new employment.

### **Employers**

We talked to employers in a social firm and in an IFD. Both organisations employed at least one individual with schizophrenia, as well people with other health conditions and without health conditions. Given the nature of their organisations these employers had considerable knowledge of employing people with mental health conditions.

### **Healthcare practitioners and academics**

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

Psychiatrist may practice in private office based practices as well as in hospital settings. Generally psychiatrists tend to focus on the clinical and medical side of treatment. As part of our work we also spoke to those from the more academic sphere, including academic psychiatrists. Whilst not having quite the same lived experience as many of the others we interviewed, their knowledge on the subject proved invaluable.

Rehabilitation specialists work in hospitals, focussing on providing in-patient and out-patient medical, social and vocational rehabilitation support (including for example, occupational therapy).

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.

## **Betreuer**

The 'Betreuer' (legal guardian) is responsible for looking after various social, medical and legal issues for their clients, to the end of protecting their welfare and helping them to continue to live independently and better integrate in society. Betreuer are usually assigned randomly to an individual (by the local court), though some have more specific types of carer duties (*Betreuerpflichten*), which might benefit different clients – for example a *Gesundheitsbetreuung* will focus on health, personal welfare, financial matters, housing, etc. Though the Betreuer will support and make recommendations, it is the court decides which services an individual will receive, and this is assessed by the MDK.

## **Social Worker**

Social Workers provide social care support for people with health conditions (and others). In this case, social workers were engaged with hospital care, often providing a vital link between in-patient provision and out-patient services, including vocational rehabilitation.

## **Carers and Family**

The carers and family members 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.

## **BMAS Civil Servant**

The Federal Ministry of Labour and Social Affairs (BMAS) develops and implements national policy on disability and employment.

## Appendix 2 Biographies of participants with lived experience

*Compiled by Kate Summers and Anthony Hind*

*Lived experience participants were recruited through supported employment services. Five were recruited through an IFD service, and five through a service similar to BTZ.*

### Participant I

The participant is 57 years old and currently works in the catering industry which she describes as her dream job. She studied nutritional science at technical college. The participant is divorced and has no children, and had her first psychotic episode in 1989.

The participant got married in 1979 and worked in several jobs, with some brief periods of unemployment, before she was diagnosed with schizophrenia. The participant suffered from severe anxiety and was seeing a psychiatrist before being diagnosed with schizophrenia. She explains that her schizophrenia developed at a time when she was employed but her boss was not treating her well, and she was the victim of domestic violence. A suicide attempt led to her being admitted to two different psychiatric facilities.

Following her stay in the second psychiatric facility she returned home and began working in the same pharmaceutical company as her husband. It was also at this time that her doctor prescribed her antipsychotic medication and discussed her condition with her employer. She found her employer very supportive and key to her condition being stable. She worked at the pharmaceutical company until 1996 when she left due to the breakdown of her relationship with her husband. The participant was admitted to a psychiatric ward following the end of her employment and started work therapy as a day patient, first training in housekeeping and then in the cafeteria.

Her current job is a catering role which she has had since 1998. She describes her workplace as providing “*an incredibly understanding network*” and says she is “*very happy to be able to work here*”. The participant says that her medication helps her to control her condition, and that her boss and aunt are her main sources of support.

Over the last 15 years the participant has taken two periods of time off work because of her condition. In terms of workplace adjustments, she does not work late shifts as she does not like locking up the premises alone late at night. The participant says she discloses her condition to her employer or colleagues when they ask. She says that she would only describe her condition broadly to colleagues, saying she has “*a mental health problem*” rather than go into detail.

She says work does not have any negative effects on her health and that in fact the best thing for her everyday wellbeing is being able to work.



## Participant II

The participant is 51 years old and is divorced. She has a 33 year old son and her highest level of education is general secondary level. She currently works in the catering industry.

The participant first noticed she was unwell while on holiday, when a cold swimming pool felt warm like a bath to her. The participant was quite seriously unwell between 1994 and 1996. It was not until her condition had fully developed that she began to receive treatment. She began taking antipsychotic medication in 1994. The participant says her mother has been a key source of support for her, and she has also had the same doctor since 1994 who she says is very supportive. She has received all of her treatment in out-patient facilities. For a period of two years she tried to not take medication with the support of her doctor, but she experienced a relapse. The medication has the side effect of making her feel tired but she sees it as necessary to stay “*more or less stable*”.

Before becoming unwell the participant worked in a factory and then a local supermarket. She says she has never had a bad job. The participant says she can work normally now but that there was a time when her condition limited her ability to work. The participant began working in her current job in 1996, and became employed on a permanent basis in 1998 following work therapy and “turbo rehabilitation” which lasted three months. The participant’s employer and colleagues are aware of her condition.

The participant has experienced some relapses of her condition, and in 1999 she had a relapse which meant she was off work for seven weeks. Last year she was off work twice for several weeks at a time as a result of two psychotic episodes. She says that work does a lot for her, and helps to stabilise and regulate her condition. She describes the most important things about work as being, “*equality, solidarity, money*”.

## Participant III

The participant is 52 years old. He is single with no children. His highest levels of education are A-levels and commercial college. He currently works for the postal workers union.

The participant explained that he first experienced hallucinations when he was a teenager, when his parents separated and he split up with a girlfriend. After completing A-levels he started university, as well as two years of civilian service. He experienced his first psychotic episode during university in 1986 and was admitted to hospital.

Following his first psychotic episode the participant trained as a legal assistant and began a two year apprenticeship. He then chose not to pursue a career as a legal assistant and undertook several manual temp jobs.

The participant describes how he did not feel integrated into society from the time that he first experienced symptoms of his illness until 1999 when he got an internship with the postal workers union. The internship led to a permanent contract. Prior to this the participant had been through professional rehabilitation which he felt was important for getting his confidence back. The participant describes the years from 1986 to 1999 as being difficult.

The participant cites work as key to his recovery and stability, alongside the support he receives from friends and family.

The participant takes medication and has delusions sometimes, but overall describes himself as managing quite well. He says he is able to work and be productive, but the side effects of the medication means he often battles with tiredness at work.

The participant has experienced several relapses of his condition, once as a legal assistant he stopped taking his medication which led to a relapse. He also experienced a psychotic episode in 1994 while he was unemployed, and at the end of 2008 changed medication and had a relapse which meant he was off work for three months.

The participant has disclosed his condition to his employer, and describes their reaction as “*pretty neutral*”. He has also told colleagues about his condition, although not always in great detail. The participant does not think his condition affects his relationship with his colleagues.

The participant explained that he receives support from colleagues, family, and a few close friends. He believes that the main factors that influence his ability to continue working are, “*taking my medication regularly, staying off alcohol, enough sleep, stable, stable environment, stable contacts.... Payment for the work. Financial*”. The financial independence that working provides was an especially important factor for the participant, making him feel integrated into society and able to lead the life he chooses.

## **Participant IV**

The participant is 48 years old. He is divorced but is now engaged to a new partner. He has one grown up son and is educated to A-level standard. He works in commerce.

The participant first developed schizophrenia in 1993 when he was working as a chemical engineer machine operator. He cites the stresses caused by shift work and the pressures of family life as ultimately leading to a nervous breakdown and his first psychotic episode. He lost his job and was hospitalised. The participant says the time in hospital gave him the space to learn about his condition, and he still keeps a close connection with the hospital even though he was an in-patient there over 20 years ago.

Following his first psychotic episode, the participant was out of formal employment for five years. During that time he sometimes helped at his father’s radio and television sales and repair business. He underwent occupational retraining during this time, and with the help of his doctor returned to work in the area of commerce.

The participant says that he has a very good work environment. He receives a 50 per cent pension because of his reduced earning capacity, but feels it is important to work and to contribute to society. He says his condition sometimes affects his ability to work, as he has ups and downs as well as trouble sleeping. He also says he finds conducting multiple tasks simultaneously difficult, and is not as stress resistant as others. His job has been designed to accommodate the effects of his condition by providing flexible working hours. His work

does not have specific set deadlines, meaning he can use his flexitime to take time away from work when he is feeling unwell. His tiredness also led to his working hours being reduced to less than full time two years ago.

The participant has had four psychotic episodes since 1993 for which he took time off work. The participant takes medication for his schizophrenia, which led to the development of a mild form of chronic arthritis. He is also taking a mild anti-depressant. He tries to stay fit and healthy by exercising regularly.

The participant describes the disclosure of his illness as happening gradually. First he told his employer he had a slipped disk, then that he was suffering from a metabolic disorder, before saying he had psychosis, after which he began to describe his condition as schizophrenia.

The participant describes work as being not only about earning money, but also “*simply participating in a normal society*”. He has been in his current job for 25 years.

## **Participant V**

The participant is 45 years old. He is married with no children and is educated to degree level. He currently works in advertising for a market research company.

The onset of the participant’s condition began during puberty. His mother suffered from severe psychosis at the time, and the participant’s own condition worsened to the point that he was living on the streets and was suicidal. The participant was then admitted to hospital, after which he was discharged to a day clinic and began living in supported accommodation. The participant believes that his recovery has been helped by rebuilding friendships and by engaging in work.

The participant hasn’t been taking medication for several years now, and the medication used to make him tired. The participant explains that his illness has an impact on his ability to work in that he is not very stress resistant and feels insecure in situations where there are a lot of people around.

As part of the participant’s recovery process he attended a work and integration programme. He was made redundant from the job he went into following the completion of the programme, and then worked for a temping agency. He did not like the temp work at all and after a few weeks was signed off sick. The participant has been in his current job since 2007.

The participant has not disclosed his condition to his current employer, as he feels his condition does not affect his ability to work and believes disclosing it would have negative effects. He has not had any psychotic symptoms in the seven years he has worked in his current job.

The participant says that his wife and family are very supportive, and that his psychotherapist was very important as he received psychotherapy for the first six months

after first starting work. He describes the most important part of his job as the atmosphere in the workplace. The role is not too challenging and not too mundane, and working in the mainstream labour market as opposed to voluntary work makes him feel more appreciated. The participant says he is very happy in his current job.

## Participant VI

Now 24, the participant began experiencing symptoms when he was in his late teens, after starting an apprenticeship as a Media Designer at an advertising agency. Since then he has completed his apprenticeship, but is now unemployed and seeking work.

He was diagnosed just before he was due to sit his final exams and after his employer and girlfriend persuaded him to seek medical help, as he explains, *“my boss and my girlfriend realised that there was more to it, that there was more wrong with me and advised me to see the doctor”*. His experience with disclosing his condition was therefore interesting as it was initiated through an attentive employer, who, after diagnosis, made provisions for the participant to work part time. Although at the time this caused significant disruption, he was able to re-sit his exams with the assistance of his employer and college teacher who helped him prepare.

Since gaining his technical diploma, he has been unable to find suitable employment and has been unemployed for approximately three years. Despite this, his passion for Media Design has led him to take on a number of voluntary projects, such as, designing a sports club's magazine. He is currently looking for a job and receives support from the employment service who, he explains, *“help ...in terms of looking for suitable jobs, accompanying me to interviews, writing applications as well. Unfortunately, I've not got a job yet, but the support is good”*. He is hopeful in finding work but believes his dream job working in *“an advertising agency with working times from ten to two”* is unrealistic.

## Participant VII

After being first diagnosed the respondent spent a significant period of time in and out of psychiatric hospital; a cycle of hospitalisation that has continued throughout his life. This affected his experiences of education and employment, although he has completed two apprenticeships and currently volunteers as an administrative assistant.

One of his first experiences with employment was as an apprentice for a landscape gardener, which he had to give up. He was, however able to continue with his studies and gain a qualification. As he describes, *“it took five years and in the end I wasn't working at my employer's anymore, but I was at college for a block of time in order to prepare for the final exams.”*

After this he successfully re-trained as a management assistant for office communication systems, which took him two and a half years to complete. Although he has not been able to progress into a role that matches his training, for the last six months he has been working four and a half hours per week as a volunteer in an administrative role. This is a position which the employment service helped him find, which has left him hopeful that he could get a

“minor-employment” job (e.g. a mini-job<sup>42</sup>) in the future. He is proactive in seeking support with his ‘personal budget’ and finds socio-therapists to be really helpful, along with his partner.

He has disclosed his condition to his current employer who has been very understanding and happy to keep his hours low to support him.

### Participant VIII

In his 40s at the time of the interview, married with two children, the participant was first diagnosed in his early 20s after experiencing a period of unemployment after leaving school. As a result of his illness he was placed in a hospital where he received support from medical staff and “*had the opportunity to get proper careers advice and look into different jobs.*”

After this the decision was taken to enrol in an apprenticeship, at a vocational college to become a Technical Draughtsman. Due to his condition, the participant was unable to complete his exams first time around, but was eventually able to complete his apprenticeship a year later.

Since gaining his qualification 15 years ago, the participant has been in steady employment with the same employer.

When asked about disclosing his condition, the respondent felt it important to do so as early as possible and had a positive experience disclosing to his current employer who has been immensely supportive: “*I said straight out that I have this illness, schizophrenia and they stand by me. They appreciate me and I can be on my own if I need to and take breaks and also mini-breaks.*”

Although he has recently had to cut back his hours at work, he is hopeful that he can remain in this current job for a long as possible.

### Participant IX

Now 44, the participant was first diagnosed with schizophrenia when she was 22 while working as an au pair in the USA. After a period of hospitalisation and unemployment she started work with her current employer, with whom she has now worked for over 15 years. She is not married and does not have any children.

For this person, work is extremely important because she feels it has a ‘stabilising effect’ and allows her ‘to lead a normal life’ which provides a “*sense of taking part in normality on the one hand, and of course, regular social contact, a task that I fulfil, enjoying work and, well, just living normally.*”

Since starting full time work she has received support from an ‘Employment Support Worker’ who she is in regular contact with and who she feels provide a good service. She has

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<sup>42</sup> [http://en.wikipedia.org/wiki/Marginal\\_employment](http://en.wikipedia.org/wiki/Marginal_employment)

disclosed her condition to her employer, who was very supportive, although she has only told 'a few select people' as she does not want it to influence people's perception of her.

## Participant X

The participant was diagnosed with schizophrenia when she was 16 and still at school. Since leaving school she has had several experiences with work and unemployment, but has now been in steady employment for two years.

After school she decided to attend university, she also worked in a bar and as a tutor to other students. Before completing university, she quit her studies to take up an apprenticeship as an Industrial Management Assistant and worked in that job for two years, as an Internal Sales Representative. After qualifying, she was unable to find a job and experienced a two year spell of unemployment in which her illness prevented her from getting and keeping a job. During this time she started working with a life coach who helped her a great deal and, as she describes "*supported me in the way that I am.*"

She has now been employed as a sales rep for an advertising merchandise company for two years, which she enjoys "*because there is no stress with other people [colleagues].*"

She currently receives support from a number of places including a Supported Employment Officer. "*I get on with her very well and I talk to her also about my hobbies.*" She also sees a social education worker, who she "*can talk about everything in my every-day life, everything that I do, so that's more psychotherapy, but it's more like coaching.*"

She has never disclosed her condition with her employers and feels she never will as they would treat her differently if they knew, even though she has a good relationship with her current boss.

## Appendix 3 Vocational rehabilitation services in Germany

Compiled by Maria Alvarez-Vaz, Victoria Shreeve and Karen Steadman

This appendix provides a brief summary of some of the main vocational rehabilitation options used by people with schizophrenia seeking employment in Germany.

The services covered are:

- **Werkstätten für behinderte Menschen (WfbM)** – Workshops for disabled people
- **Integrationsfirmen** – Social firms
- **Integrationsfachdienst (IFD)** – Integration services
- **Rehabilitationseinrichtungen für psychische Kranke und Behinderte (RPK)** – Rehabilitation institutions for people with mental conditions and disabilities
- **Berufstrainingzentrum (BTZ)** – Vocational training centres
- **Unterstützte Beschäftigung (UB)** – Supported employment

Based on the data provided below, table A provides a summary of the numbers and proportions of people with mental health conditions using some of these provisions, based on the estimated provided. The purpose to provide the reader with an idea of the relative service use.

**Table A: Estimated use of selected VR services by people with mental health conditions**

Service type (year data collected)	Total clients	Proportion of clients with mental health condition	Estimated number of clients with mental health conditions
WfbM (2014)	303,000	19.8%	<b>59,994</b>
Integrationsfirmen (2012)	10,164	19.4%	<b>1,972</b>
IFD (2010)	74,000	25%	<b>18,500</b>
UB (2012)	3,000	15%	<b>450</b>



## Werkstätten für behinderte Menschen (WfbM)

### What is the service?

Sheltered workshops, also known as workshops for disabled people (WfbM), offer employment exclusively for people with disabilities. WfbM are for the long-term unemployed; those who are struggling to enter the labour market and for those who have left the labour market (Brieger, Becker, Bäuml, Pitschel-Walz, & Weig, 2007). Anyone, regardless of type or severity of disability, is eligible to enter a WfbM, provided they can meet a minimum level of job performance.

According to the Social Code the main purpose of a WfbM is to offer the necessary support for disabled people to develop their social skills and confidence in the workplace, and so to help them secure employment (§39 SGB IX). The legal basis can be found in the 9<sup>th</sup> book of the social code. Funding comes through 'rehabilitation funds' (*Rehabilitationsträger*), which draw on a number of sources.<sup>43</sup>

WfbM provide two types of service:

- Vocational training – in the training area or *Berufsausbildungsbereich*; and
- Employment – in the working area or *Arbeitsbereich*.

Vocational training offers a basic course (*Grundkurs*) and an advanced course (*Aufbaukurs*), each lasting one year. The *Grundkurs* provides some basic training in work processes and behaviours, e.g. manual skills and the development of social and work habits, in order to develop self esteem and improve employability. The *Aufbaukurs* teaches a broader range of skills and to a more advanced level, as well as improving stamina and resilience.

After vocational training, individuals will usually progress to employment in the 'working area' of the WfbM. WfbMs operate in a variety of sectors, with work including: product assembly (ranging from electronics to carpentry to metal work), catering, secretarial services, textile processing, gardening and building maintenance<sup>44</sup>. There are a broad number of work options within WfbMs which take into account a range of employee interests and aptitudes, as well as different type and severity of disability. WfbM are intended and help to provide as similar an environment to the general labour market as possible.

Those unable to fulfil the requirements for employment in the *Arbeitsbereich* may be placed in special departments within the WfbM or into day centres (*Tagesförderstätte*). In some cases, individuals can also progress straight from vocational training into the general labour market.

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<sup>43</sup> the statutory health insurances (*gesetzlichen Krankenkassen*), Federal Employment Agency, statutory accident insurance (*gesetzlichen Unfallversicherung*), statutory pension insurance institutions (*Träger der gesetzlichen Rentenversicherung*), war victims support institutions (*Träger der Kriegsopferversorgung und die Träger der Kriegsopferfürsorge*), public youth welfare providers (*Träger der öffentlichen Jugendhilfe*), social welfare institutions (*Träger der Sozialhilfe*)

<sup>44</sup> Integrationsfirmen in Deutschland. Available at: <http://www.rehadat.info/export/sites/einstieg/downloads/VerzIntFirmen.pdf>

WfbM are run by a workshop director (*Werkleiter*), who has technical and professional experience, and a qualification in special education. Staff also include specialist employment/training advisors who provide social, pedagogic and labour support. Health professionals may also be contracted, via the medical service.

During the admission/entrance process (*Eingangsverfahren*) and vocational training, WfbM employees are either paid an education/training allowance (*Ausbildungsgeld*) by the Federal Employment Agency (*Bundesagentur für Arbeit*) (€63 for the first training year and €75 for the second), or they receive an transition allowance (*Übergangsgeld*) from the rehabilitation funds (§125 SGB III). Once they enter the *Arbeitsbereich*, employees are paid a minimum monthly wage (*Grundbetrag*) of €75 (§138 SGB IX) plus *Arbeitsförderungsgeld* (§43 SGB IX), this monthly salary can also increase depending on job performance. However, the average pay received by individuals working in WfbM is not comparable to the open market, estimated at €180 a month (Doose, 2012).

People working in the *Arbeitsbereich* are legally employed (§138 SGB IX) and do not appear in the unemployment figures. They are covered by compulsory health, nursing, pension and accident insurance. After 20 years of employment, individuals are eligible for retirement because of their reduced earning capacity (*Erwerbsminderung*). Also, in the case of their wage or pension not covering an individual's basic needs they may be eligible for other incapacity benefits (*Grundsicherung*).<sup>45</sup>

### **Prevalence and Users**

Besides regular employment, WfbM is by far the most common type of work participation for disabled people in Germany. WfbM have a strong presence, they are heavily invested in and have good geographical coverage. This contrasts with other supported employment services which have been subject to increasing financial pressures.

According to BAG WfbM statistics there are 685 "main" WfbM in 2014<sup>46</sup>. Both the number of workshops and the number of people in them have been growing (Ward et al., 2007), in 2014, there was an estimated 303,000 WfbM employees (including 31,000 in vocational training and 256,000 in the *Arbeitsbereich*), up from 271,000 in 2011<sup>47</sup>. A steady increase in employees in WfbM has been noted even in times of economic growth (Waldschmidt et al., 2009). The Federal Ministry for Labour and Social Affairs (Detmar et al., 2008) found that between 2001 and 2006 there was a 16 per cent increase in the number of sheltered workplaces and a 23 per cent increase in the number of people participating in WfbM, with a large proportion (48 per cent) coming directly from special-needs schools (Klinkhammer et al., 2012).

It appears that numbers of employees with mental health conditions are also increasing. In 2012, the Federal Working Group for sheltered workshops (BAG WfbM) estimated that 19.8

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<sup>45</sup> Einfach teilhaben 'Verdienst und soziale Sicherung'. Available at: [http://www.einfach-teilhabe.de/DE/StdS/Ausb\\_Arbeit/Werkstaetten/Arbeitsentgelt/arbeitsentgelt\\_node.html](http://www.einfach-teilhabe.de/DE/StdS/Ausb_Arbeit/Werkstaetten/Arbeitsentgelt/arbeitsentgelt_node.html)

<sup>46</sup> BAG-WfbM "Die BAG WfbM" Available at: <http://www.bagwfbm.de/page/24>

<sup>47</sup> BAG-WfbM "Die BAG WfbM" Available at: <http://www.bagwfbm.de/page/24>

per cent of the WfbM employees had a mental disability<sup>48</sup>, compared to 17 per cent in 2011 (BMAS in 2011, cited in Doose (2012)). Other groups employed at WfbM are people with learning disabilities (77.5 per cent) and physical disabilities (3.3 per cent) (BIH, 2013).

### **Movement in and out of the service, and between services**

Referrals to the WfbM are made by the rehabilitation team at the employment agency (*Arbeitsagentur*)<sup>49</sup>. The team often consults with psychological and medical specialists and may include an integration advisor (*Integrationsberater*).

When entering the WfbM, individuals undertake an admission/entrance process (*Eingangsverfahren*) run by the WfbM Technical Committee (*Fachausschuss*). This process (taking approximately three months) is to determine whether the workshop is the appropriate place for the individual, as well as which areas and services of the workshop are most appropriate. An integration plan (*Eingliederungsplan*) outlining the proposed next steps is developed and sent to the funders, and is documented by the WfbM social service department (*Sozialer Dienst*).

Some people may not remain in the WfbM, but transfer to other services, such as day-centres, or other vocational services (e.g. BBW) as recommended by the Technical Committee (Biermann, 2007).

When transferring to the general labour market, employees can access support through the integration service (*Integrationsamt*) and employment agency (*Arbeitsagentur*), who work together with the WfbM to support external placement (as outlined in the Social Code SGB IX 136). Integration offices fund WfbM to promote the transition of disabled people into general employment (€36.2 million in total in 2012), however this funding differs depending on the state (BIH, 2013).

Placement outside the WfbM might occur in three ways<sup>50</sup>:

1. Outsourced work placements (*Außenarbeitsplätze*): Individuals are placed in companies in the general labour market but maintain their status as a WfbM employee. This aims at providing experience of the open labour market and sense of inclusion in society<sup>51</sup>. The placement is usually on an individual basis.<sup>52</sup>
2. Internships in companies in the general labour market. These internships are

<sup>48</sup> BAG-WfbM "Menschen in Werkstätten" <http://www.bagwfbm.de/page/25>

<sup>49</sup> Frie Hansestadt Bremen "Fachliche weisung" [http://www.soziales.bremen.de/sixcms/media.php/13/07\\_Zugangsverfahren%20WfbM%20u.%20Tagesst%20E4tte%20bearb.%202012.02.07-bf-.pdf](http://www.soziales.bremen.de/sixcms/media.php/13/07_Zugangsverfahren%20WfbM%20u.%20Tagesst%20E4tte%20bearb.%202012.02.07-bf-.pdf)

<sup>50</sup> Talentplus: REHADAT. "Wege auf den allgemeinen Arbeitsmarkt". Available at: [http://www.talentplus.de/arbeitnehmer-bewerber/neuer\\_Job/Beschaefigungsmoeglichkeiten/Besonderer\\_Arbeitsmarkt/Werkstaetten\\_fuer\\_behinderte\\_Menschen/Wege\\_auf\\_den\\_allgemeinen\\_Arbeitsmarkt/index.html](http://www.talentplus.de/arbeitnehmer-bewerber/neuer_Job/Beschaefigungsmoeglichkeiten/Besonderer_Arbeitsmarkt/Werkstaetten_fuer_behinderte_Menschen/Wege_auf_den_allgemeinen_Arbeitsmarkt/index.html)

<sup>51</sup> Rehadat Bildung "Wege auf den allgemeinen Arbeitsmarkt". Available at: [http://www.rehadat-bildung.de/de/betrieblich-ausserbetrieblich/in-wfbm/Wege\\_auf\\_den\\_Arbeitsmarkt/](http://www.rehadat-bildung.de/de/betrieblich-ausserbetrieblich/in-wfbm/Wege_auf_den_Arbeitsmarkt/)

<sup>52</sup> Rehadat Bildung "Wege auf den allgemeinen Arbeitsmarkt". Available at [http://www.rehadat-bildung.de/de/betrieblich-ausserbetrieblich/in-wfbm/Wege\\_auf\\_den\\_Arbeitsmarkt/](http://www.rehadat-bildung.de/de/betrieblich-ausserbetrieblich/in-wfbm/Wege_auf_den_Arbeitsmarkt/)

designed to test the individual's work capacity (*Belasbarkeit*). The internship may end with a job placement, otherwise, the IFD will continue searching for a suitable job after the internship completion.<sup>53</sup>

3. Social firms (*Integrationsfirmen*). Where regular employment is available within reasonable timescales, WfbM employees can be placed in social firms with outsourced jobs. In order to secure a placement in the social firms, the scope of the outsourced WfbM jobs must be agreed by the integration office<sup>54</sup>. Social firms are discussed in more detail below.

Evidence indicates that in reality, transferring from sheltered workshops to the general labour market does not happen frequently. Between 2010 to 2012 only 0.2 per cent of WfbM employees went on to jobs in the open labour market (Doose, 2012). Undertaking outsourced work placements is more common (Doose, 2012). In 2006, only 3 per cent of all WfbM places were being conducted in external companies, however attempts have been made to increase this in recent years, in Bamberg and Hamburg up to 23 per cent of workshop employees work in companies in the community (Doose, 2012). Placements mostly involve medium sized companies who are often the easiest cooperation partners. Special school and Federal Employment Agencies have been suggested as the main obstacle to success in the transition from WfbM into the general labour market (Detmar et al., 2008).

A further problem is the risk of employers taking advantage of these attractive contracts; individuals can still be officially employed and paid by the WfbM, therefore employers get their labour but do not have to provide the same benefits (Detmar et al., 2008)<sup>55</sup>. To solve this, Rheinland Pfalz introduced the "budget for employment" (*Budget für Arbeit*), which supports transition directly into employment, rather than via outplacement, through subsidising the companies (e.g. wage cost subsidies).<sup>56</sup>

A barrier for individuals making decisions about transitioning into the open labour market is the risk of failure and therefore the risk of losing their limited capacity benefit (*Erwerbsminderungsrente*), this is however regulated at regional level and there might be exceptions (Diakonisches Werk der Evangelischen Kirche in Deutschland, 2009). The benefit is stopped when an individual's salary is higher than €450 and/or when the individual's health status improves so that they are able to work at least six hours a day, five

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<sup>53</sup> <http://www.ifd-bw.de/leistungen-fuer-schwer-behinderte/beschaefigte-der-werkstaetten-fuer-behinderte-menschen.html>

<sup>54</sup> <http://www.bag-if.de/wp-content/uploads/2011/01/BIH-Empfehlungen-IP-Stand-27102010.pdf>

<sup>55</sup> Detmar et al. (2008: 12-13) stated that a permanent wage cost subsidy for the companies can actually bring a breakthrough in comparison with the traditional promotion structure, because the funding resources for vocational training and employment fields for the WfbM could be used as incentive for the regular companies.

<sup>56</sup> In the context of this initiative, in January 2013 a concrete programme called "aktion5" was introduced which aims at promoting and supporting the placement and labour stabilization of severely disabled people in the general labour market. The benefits depend on the type of employment contract –temporal contract must be of at least twelve months of duration- and comprise bonuses for the hiring, for the training and wage cost subsidies. WfbM leavers are one target group of this programme and it is stated that the regional integration office of LVR (Landschaftverband Rheinland) shall only run with the wage cost subsidies in case of transition from the training field of a WfbM or in case that the training or employment contract in the open labour market avoids the admission in a WfbM. The application will run through the regional IFD Westalen and IFD Rheinland. <http://www.aktion5.de/index.html>

days a week, or they are able to work part-time for three hours each day. The benefit can be reinstated if partial or total incapacity is diagnosed again (Bundesministerium für Arbeit und Soziales, 2012).

## Integrationsfirmen

### What is the service?

*Integrationsfirmen* (also known as *Integrationsprojektes*) are companies (or departments) which specifically employ people with severe disabilities, but which operate in the open labour market. These are also known as ‘social firms’. The precursors of the *Integrationsfirmen* were ‘self-help firms’, which were founded in the 1970s in response to increasing unemployment amongst disabled people.<sup>57</sup>

*Integrationsfirmen* carry out both a social and an economic task – the integration of severely disabled people being economically competitive. At least 25 per cent of people employed in *Integrationsfirmen* will have severe disabilities. For reasons of business competitiveness the proportion of severely disabled people generally does not exceed 50 per cent.

*Integrationsfirmen* provide training and employment, to the end of supporting and preparing severely disabled individuals to find jobs in the general labour market (BIH, 2012). They also provide employees with a range of support, including psychosocial care provided by a specialist or appropriately qualified staff member.<sup>58</sup>

The legal basis for *Integrationsfirmen* is in the Social Code (§132–135 SGB IX). Funding can be complex. For example, *Integrationsfirmen* can obtain up to €200/month for each employee with severe disabilities in return for the creation of workplaces for people with disabilities (SGB III). Another funding source is the duty of employment quota/levy (*Ausgleichsabgabe*) (§134 SGB IX) accessed through the regional integration offices (*Integrationsämter*) (§102 3 SGB IX)<sup>59</sup>. Employee wages and holiday entitlement and determined through local collective bargaining. Guidance on pay rates is provided from integration offices. Individuals can also obtain benefits in case they need to make workplace adjustments at the *Integrationsfirmen* (§134 SGB IX, §27 SchwbAV).

### Prevalence and Users

The target groups (as outlined in the Social Code §132 SGB IX) for *Integrationsfirmen* are:

- People with mental or emotional disabilities, severe physical, sensory or multiple disabilities for whom participation in the general labour market is difficult or impossible.

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<sup>57</sup> <http://www.bagbbw.de/service/lexikon/eintraege/integrationsprojekt/>

<sup>58</sup> LVR “Die Förderung von Integrationprojekten”. Available at: [http://www.lvr.de/media/wwwlvrde/soziales/menschenmitbehinderung/arbeitundausbildung/dokumente\\_229/integrationsprojekte/Foerderrichtlinien-IP\\_2012.pdf](http://www.lvr.de/media/wwwlvrde/soziales/menschenmitbehinderung/arbeitundausbildung/dokumente_229/integrationsprojekte/Foerderrichtlinien-IP_2012.pdf)

<sup>59</sup> BIH: “Empfehlungen der Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen zur Förderung von Integrationsprojekten nach §§ 132 ff. SGB IX”. Available at: [https://www.lwl.org/abt61-download/PDF/Integrationsprojekte/BIH-Empfehlungen\\_IP\\_Stand\\_23\\_04\\_2012.pdf](https://www.lwl.org/abt61-download/PDF/Integrationsprojekte/BIH-Empfehlungen_IP_Stand_23_04_2012.pdf)

- Severely disabled people, who participated in a pre-course for a WfbM or in a psychiatric institution for the transition to a department or office in the general labour market.
- People with disabilities who have completed formal education, but who need to take part in an *Integrationsfirmen* to have a prospect of employment in the open labour market.

The number of *Integrationsfirmen* has increased steadily in recent years. In 2012 there were 726 funded, up from 684 in 2011. Numbers have more than doubled over ten years – there were 314 in 2002 (BIH, 2012, 2013).

Employee numbers are growing too – in 2011, 25,190 people (both severely disabled and non-disabled) were employed by *Integrationsfirmen*, an increase of 580 people on the previous year, 37 per cent (9,265) of employees were severely disabled. By 2012, 10,164 people with severe disabilities were employed in *Integrationsfirmen*. The proportion with mental health conditions was 19.4 per cent, while learning disabilities made up 28.5 per cent (BIH, 2013). It has been suggested that although in the past people with mental health conditions formed a large client base for services, in time they have decreased as a proportion of the *Integrationsfirmen* workforce (despite an overall increase in employees).

### **Movement in and out of the service, and between services**

Many employees are referred to *Integrationsfirmen* from the WfbM. Since 2006 the number of WfbM employees moving into the *Integrationsfirmen* has increased continuously (BIH, 2011). The referral goes through the regional integration offices, normally through the *Integrationsfachdienste* (IFD).

## **Integrationsfachdienst (IFD)**

### **What is the service?**

IFD put measures in place for the participation of (severely) disabled people in the workforce, on behalf of the *Bundesagentur für Arbeit* (Federal Employment Agency), the rehabilitation funds and the integration offices.

The IFD perform tasks including: vocational guidance, job searching, training, stabilization and job retention, and the provision of advice to disabled people, employers and colleagues. The professionals involved in the IFD service tend to have psychosocial or work educational qualifications<sup>60</sup>, and may include social workers and educators.

There are two types of IFD service, which are funded separately. IFD-V (*IFD-Vermittlung* or 'mediation') specialises in getting disabled people into work, including support for employers in the placement of disabled people, e.g. six month internships, preparation of applications,

<sup>60</sup> BIH INTEGRATIONSÄMTER "Integrationsfachdienst". Available at: <http://www.integrationsaemter.de/Fachlexikon/Integrationsfachdienst/77c438i1p/index.html>



etc. IFD-B (*IFD-Begleitung* or ‘accompaniment’) focuses on in work support – aimed at overcoming any performance difficulties, social adaptation problems, conflicts in the workplace, etc. (Aktion Psychisch Kranke, 2007).<sup>61</sup>

IFD may also utilise funding for supported employment (*Unterstützte Beschäftigung*, UB) (Doose, 2012). This funding supports the provision of an evidence based approach for supporting people with learning disabilities and mental health conditions to find employment. Individual Placement and Support (IPS)<sup>62</sup> supported employment is an evidence-based approach for people with severe mental health condition. Although the IPS model has been mainly tested in the US and UK, it is possible to identify similarities between IFD and the eight principles of IPS.

The duration of IFD support varies according to the rehabilitation institution the individual participates in. Funding agreements and tendering scenarios may dictate this. The integration office (*Integrationsämter*), Federal Association of the integration offices (BAG-IF) and main welfare agencies (*Bundesarbeitsgemeinschaft der Integrationsämter und Hauptfürsorgestellen*, BIH<sup>63</sup>), can reimburse the costs of integration services. Funding may be based on social security contributions (and therefore be dependent on an individuals’ employment history). Alternate natively, funding can come from the duty of employment quota-levy (*Ausgleichsabgabe*), and therefore is reliant on the number of larger companies in the region (i.e. those with more than 20 employees). One expert noted that there was more pressure in urban areas where there were more small businesses. The legal basis for this can be found in §109-115 and §102.3 SGB IX.

Although income to IFD has increased since 2007, duties have also increased since then, including the proviso around the creation of social firms, ongoing in work support for employee and employers, and measures directed at the transition from WfbM into employment (Aktion Psychisch Kranke, 2007). It has been suggested that a decrease in duty of employment levy income has led to an increased financial pressure on IFDs, leading some to reduce their services, in particular, in terms of placement into work (IFD-V) (BIH, 2013).

Although the intention was close cooperation between the federal employment agency, the integration office and the IFD (BAG BBW)<sup>64</sup>, in reality, this has not been the case. BMAS claims that clear and constructive cooperation is found only rarely (Detmar et al., 2008).

### **Prevalence and Users**

The target groups for IFD are defined in §109 SGB IX as: severely disabled people with a special need for counselling or who come from WfbM; severely disabled school leavers; and,

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<sup>61</sup> <http://www.talentplus.de/lexikon/I/integrationsfachdienst.html>

<sup>62</sup> Centre for Mental Health ‘Individual Placement and Support (IPS)’  
<http://www.centreformentalhealth.org.uk/employment/ips.aspx>

<sup>63</sup> <http://www.integrationsaemter.de/>

<sup>64</sup> Die BBW “Integrationsfachdienst (IFD)” Available at:  
<http://www.bagbbw.de/service/lexikon/eintraege/integrationsfachdienst-ifd/>



disabled people who are not severely disabled, but who need special support or vocational guidance. The IFD has been criticised for failing to reach this target population. Its critics say that in being run by the Federal Employment Agency it has prioritised simply the reduction of unemployment above other goals. For example, focus has increasingly moved away from supporting those in school or in sheltered workshops, as these groups were not 'unemployed' and therefore not the concern of the Agency (Doose, 2012). The IFD is not always used as intended, for example, the intention was to primarily use IFD for the training support of young people with learning disabilities, however it has increasingly been supporting young people with mental disabilities (Detmar et al., 2008).

IFD are themselves employers of people with severe disabilities – in 2010 it was estimated that 9,000 out of its 25,000 employees were severely disabled (36 per cent, though the original aim was for 50 per cent disabled/non-disabled workforce).

IFD services are estimated to have supported 66,000 people with disabilities in 2008 (European Commission, 2011). In 2010 they supported nearly 74,000 people with disabilities, found over 8,000 new jobs and supported about 13,500 severely disabled people. About 50 per cent of the clients were employed and needed support to maintain their jobs, 43 per cent were unemployed, 5 per cent were students who were still at school and 2 per cent came from a sheltered workshop.

IFD services are seen as particularly relevant for people with mental health conditions (Aktion Psychisch Kranke, 2007). Although demand for IFD amongst individuals with mental health conditions has increased in recent years, specialised services for mental health have decreased. There are fewer service users with a mental health condition in the IFD-V than in the IFD-B. In both services though individuals with mental health conditions are increasingly becoming the minority (Aktion Psychisch Kranke, 2007). From 1998 to 2006, the proportion of people with mental health conditions in IFD decreased from around 55 per cent to 25 per cent, however they remained the second largest group (after people with physical disabilities) (Aktion Psychisch Kranke, 2007). Figures from 2010, 2011, and 2012, show that people with mental health conditions remain around 25 per cent of the user population – in 2011, 26.3 per cent (17,464); and 2012, 22.4 per cent (18,341) (BIH, 2013; Doose, 2012). One IFD contacted during this study estimated that around 5 per cent of their clients would have schizophrenia (10 out of 180), a considerable decrease on service composition in the 1980s.

It has been suggested that a barrier to individuals with mental health conditions accessing the IFD is that owning a disability card is a pre-requisite in almost all the federal states. It is only in [Rhineland-Palatinate](#) that "alternative evidence" (*Ersatztatbestände*) can still be used, which can allow people who do not have a severe disability, but might encounter special difficulties in their placement, to enter the IFD (Aktion Psychisch Kranke, 2007).

### **Movement in and out of the service, and between services**

Research has identified a number of pathways through which clients may be referred to IFD

services:

- Via a social worker in a psychiatric clinic. There is a lack of data on the likelihood of this, referrals are dependant on individual awareness and interest, though it has been suggested that it is more common in some cities than others, and perhaps as few as a quarter of social workers are likely to inform patients about services in this way.
- By word of mouth.
- Through office-based psychiatrists. Some work closely with the IFD and inform patients about their service, however as with social workers referrals are dependant on individual awareness and interest.
- Employer requests. Employers who are aware of the service may approach an IFD directly to get support to help them retain their employee.
- An IFD may also attend health facilities to promote their services and raise awareness both among individuals and health professionals, to facilitate further referral. It was noted in our research however, that the ability to do this has been severely affected by financial constraints.

IFD may also link to other services. The following examples of relationships were identified in the research:

- Referrals may occur between IFD and BTZ (*Berufstrainingszentrum* – vocational training centre) depending on the clients needs, e.g. after completing the period of in-job support offered by the BTZ, a disability-pass holder might move to the IFD for further support. Or if the person is not yet employed, the IFD may refer them to the BTZ for training and support (this was identified in IFD Cologne<sup>65</sup>).
- IFD advise employees of WfbM, for example, around accessing internships in the general labour market. A WfbM may have a regular point of contact in an IFD, these individuals might be employed by or work as an associate of the WfbM (Detmar et al., 2008).
- IFD collaborate with schools to facilitate students' transition into general employment after completing school. This support aims to prepare them for future employment, job placements and employment retention. The IFD inform the integration office and the rehabilitation funds about their support services. The cooperation between the school, the integration advisors and the IFD is considered a part of *berufsvorbereitenden Maßnahmen* (measures preparing for employment) (KVJS, 2008).

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<sup>65</sup> BTZ Köln "Der Trainingsverlauf im BTZ" Available at: <http://www.btz-koeln.de/content/e364/e396/>

- IFD can also refer candidates to *Integrationsfirmen*. For this, the *Integrationsfirmen* informs the employment agency and the IFD of any vacancies and the skills needed. The IFD and the *Integrationsfirmen* will support the candidate during the application process<sup>66</sup> and once employed in the *Integrationsfirmen* they receive the support necessary for integration.

## Rehabilitationseinrichtungen für psychische Kranke und Behinderte (RPK)

### What is the service?

RPK offer rehabilitation services for people with mental health conditions, near to their place of residence and fitting around their day to day life. They particularly focus on people with schizophrenia or with schizotypal and paranoid, emotional, personality and behavioural impairments. The RPK are small organizations (10 - 50 places) and are joined up at a regional level.

RPK offer both medical and vocational support at the same time. The service is tailored to the individual, according to the support and development needs for the rehabilitation plan. The range of services provided varies locally. The RPK aims to restore an individual's ability to participate in both employment and a private life. Rehabilitation aims to prevent future problems with participation in professional and social life, through putting in place early measures to eliminate, improve or prevent aggravation of the disability. At RPK people with mental health conditions also receive support to accept their condition and develop social competencies for the labour market.

The different services of the RPK are as follows:

- Information and guidance about rehabilitation and rehabilitation services.
- Medical rehabilitation (max. twelve months): medical treatment in psychiatry, psychotherapy and psychopharmacology; psycho-education; conversations with relatives; ergotherapy and burden test; psychiatric nursing; physiotherapy and sport/movement therapy, psychosocial support (including employment); health education.
- Vocational rehabilitation (max. twelve months): services for clarifying job suitability and job trials (max. six weeks), training measures, vocational adaptation (up to nine months), in work psychosocial support, and support for admission and training in a WfbM (up to three months for the admission).

RPK normally have a multidisciplinary rehabilitation team, composed of physicians, psychologists, occupational therapists, ergotherapists/job educators, physiotherapists, social

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<sup>66</sup> KVJS "Absprache zum Verfahrensablauf" Available at: [http://www.kvjs.de/fileadmin/dateien/Schwerbehinderung/Integrationsunternehmen/Verfahrensabsprache\\_IP\\_IFD\\_Endfassung\\_DE\\_PF\\_2011\\_0.pdf](http://www.kvjs.de/fileadmin/dateien/Schwerbehinderung/Integrationsunternehmen/Verfahrensabsprache_IP_IFD_Endfassung_DE_PF_2011_0.pdf)

workers/social pedagogues, health and nursing professionals (with experience in psychiatry), and professionals in vocational rehabilitation (BAR, 2010).

The legal basis for funding the RPK is laid out in §111 SGB V. It is funded in part by the main rehabilitation beneficiaries, such as pension insurance (*Rentenversicherung*), health insurance companies (*Krankenkassen*) and the federal employment agency (*Agentur für Arbeit*), whose objectives for the rehabilitation might differ slightly. The RPK recommendation agreement (RPK-Empfehlungsvereinbarung) outlines the relationship between the health insurance carrier, pension plan providers and the federal employment agency (BAR, 2010).<sup>67</sup>

### **Prevalence and Users**

RPK services are particularly aimed at younger people with psychotic or bipolar conditions who might be at risk of developing a long-term disability and have already been hospitalised long-term because of their mental health condition.

Normally, this service is for people who need to make use of supervised accommodation, day clinics and for whom the integration in employment is highly challenging.

### **Movement in and out of the service, and between services**

To be admitted to the RPK, some social and medical requirements must be met. Primarily there must be an imminent health-related or manifested impairment which is preventing participation, and requires a multidimensional and interdisciplinary approach to rehabilitation.

The application for RPK must be issued through the rehabilitation carrier according to the process established in §14 SGB IX, accompanied by a series of required documents. After the results of the medical rehabilitation, the RPK institution and the individual will agree on a rehabilitation plan and a plan for participating in working life, which must be approved by the rehabilitation carrier.

According to the annual BAG RPK report of 2011, people in RPK were mainly referred by psychiatric clinics (55 per cent), rehabilitation carriers (16 per cent), office-based specialized physicians (8 per cent), psychiatric out-patient institutes (5 per cent) and relatives (5 per cent). Other referral paths were advice centres (*Beratungsstellen*), legal guardians (*betreuer*) and office-based specialised psychotherapists.

The RPK identifies the requirements for a permanent and sustainable reintegration in the general labour market through understanding an individual's vocational aptitude and interests, as well as through work experience (e.g. internships in companies) (BAR, 2010).

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<sup>67</sup> The *RPK-Empfehlungsvereinbarung*, together with the diagnosis and the rehabilitation objectives, comprises the personal and structural requisites for the RPK and the responsibilities of the rehabilitation carriers. It also describes the medical services needed for the rehabilitation, as well as the vocational services needed for the integration in employment. The frame of reference of the *RPK-Empfehlungsvereinbarung* is the ICF3 (International Classification of Functioning, Disability and Health), whose fundamental basis is the functional health.

Within two weeks of completing the vocational rehabilitation, the RPK prepares a report on the progress made and results. The report focuses on socio-medical statements about the ability to work, the possibilities for long-term professional integration and the current state of professional and social integration. The final report can also recommend to what extent further qualification measures should be carried out.<sup>68</sup>

BAR (2000) named the following outcomes as the common next steps after rehabilitation in the RPK: general employment (25 per cent); employment in an *integrationsfirmen* (9 per cent); enrolment in a degree, vocational training in a *Berufsbildungswerke* (vocational training centre for young people with disabilities) or (re)training in a *Berufsförderungswerk* (centre for further vocational further training) and after that, looking for a job (14 per cent); or, sheltered employment in a WfbM (21 per cent).

In 2011 BAG RPK reported that 850 clients completed the RPK medical rehabilitation while 334 left prematurely<sup>69</sup>. Of these, 32 per cent continued with some aspect of vocational participation at a RPK, 16 per cent continued with further training, and 11 per cent went into the general labour market. Of the 273 people who completed the vocational rehabilitation, 26 per cent went into further training, while 38 per cent went into the general labour market. Together that makes a total of 229 people going into the general labour market and 217 into (re)training measures – with 206 remaining jobseekers.

## Berufstrainingzentrum (BTZ)

### What is the service?

BTZ are vocational training centres for people with mental health conditions who have already completed some vocational training. They offer medical and vocational support for reintegration into the general labour market or into further training. To be eligible, individuals should be able to work for at least four hours a day.

The services offered and the processes undertaken will vary depending on the service itself, and the individual's needs. Some of the key elements are briefly discussed below:

- Assessment. Individuals will work with a job coach (supported by psychologist/social worker) to ascertain their skills, experience and abilities, as well as their employment aspirations, to the end of finding suitable areas for work, and identifying suitable training. Consultation with the industry in question may also occur.
- Training or retraining. Undertaken to obtain skills or a qualification to move into employment in a desired industry. Most training takes place within the BTZ, but there are also opportunities for internships<sup>70</sup> at external companies, which may lead to permanent roles. The process of actively seeking internships is seen as part of

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<sup>68</sup> <http://www.bar-frankfurt.de/>

<sup>69</sup> <http://www.bagrpk.de/>

<sup>70</sup> For example, the model identified in BTZ Rhein-Neckar consist of two or three internships, each of a progressively longer period of time, aiming at the hiring of the intern by the company after the last internship.

training. Training might also focus on general professional and social/interpersonal skills if required.

- Support during job searching and finding and placement in employment. Ongoing counselling and support in the workplace is also offered.

BTZ training is usually over a period of 12-15 months, though support beyond this time may be available if required. For example, in the BTZ Duisburg, they plan twelve months for professional training: initial training (three months), company training (three months), internship (one month), company training (three months), final internship (two months – during the integration stage), and follow up support (*Nachbetreuung*) of up to twelve months (this can vary though, e.g. BTZ Köln offers six months *Nachbetreuung*). This follow-up support aims at guaranteeing employment/retraining, with personal advice and support during application processes and placement services, similar to the IFD.

BTZ normally have an educational/psychological and administrative head and manager, and include psychologists, occupational therapists, social workers and job coaches/occupational trainers in all business branches. They cooperate closely with rehabilitation and integration advisors, external healthcare professionals and specialised information offices.

The §35 SGB IX refers to institutions providing vocational rehabilitation. The federal working group is BAG BTZ. BTZ is funded through the vocational rehabilitation funds. Funding normally comes from the pension fund (*Rentenversicherung*), the Federal Employment Agency – depending on previous social security payments, or employer insurance should the condition be work related.

People might be paid a transition allowance (*Übergangsgeld*) or an education/training allowance (*Ausbildungsgeld*). When BTZ clients are placed permanently in the labour market, they will revert to a full regular salary, or the employer may apply for an integration subsidy (*Eingliederungszuschuss*). Under this, the Pension fund (*Rentenversicherung*) or Federal Employment Agency pay a proportion of the salary for a certain time. After this period the employer will have to pay the full wage. The rate of subsidy is decided by the pension fund following general guidelines.

### **Prevalence and Users**

There are 24 BTZ in Germany, helping adults (over 18) with mental health conditions to re-enter the general labour market. This includes school leavers and graduates. Eligibility is not dependent on having a disability pass, but is reliant on information about their diagnosis and previous work experience.

BTZ are mainly used by those who are currently unemployed – the focus is on retraining people who have had to leave their job due to illness, in order to allow them to return to that area or a similar area of work.

According to a 2012 report from BTZ Hamburg<sup>71</sup>, clients were diagnosed with the following conditions: affective disorders (34.4 per cent), schizophrenia related impairments (18.5 per cent), neurotic/stress/somatoform disorders (16.9 per cent), personality/behaviour disorders (20.7 per cent) and of other mental impairments (9.6 per cent).

### **Movement in and out of the service, and between services**

BTZ providers form a network with partner organisations and rehabilitation institutions, who might take on clients (e.g. ARGE BFW, BAG IF, BAG BBW, BAG UB, BAG WfbM, etc.)<sup>72</sup>. They maintain close ties to in-patient and out-patient psychiatric facilities and services as well as local self-help groups. A common link is that a holder of a disability pass may be able to access further support from an IFD once placed in a job. As discussed above, there is however no prerogative to do this and it may differ between states and areas (*Landschaftsverbände*). Employers may contact BTZ directly to request an intern, though this is less common.

Data from BTZ Rhein-Neckar<sup>73</sup> in 2011 showed that at six months and twelve months after the training, over 60 per cent of clients were integrated into regular employment or training/retraining places. 2012 data from BTZ Hamburg<sup>74</sup> showed that six months after the integration training (*Anpassungstraining*), 53.7 per cent had found roles in the general labour market, whilst 31.2 per cent were unemployed and seeking work.

Data from BTZ Rhein-Neckar on client satisfaction and well-being showed improvements in working capabilities (66 per cent), social skills (60 per cent), self-confidence (75 per cent) and mental health status (77 per cent).

Long-term health benefits are also inferred – when surveyed 12-15 months after completion of training 71 per cent of participants were no longer receiving treatment, and 68 per cent claimed to no longer experience acute mental illness. Though this data does not specify outcomes for clients with schizophrenia, the BTZ Rhein-Neckar estimated that people with symptoms of schizophrenia accounted for around 25 per cent of their annual clients. It was further suggested that employment outcomes were particularly good for clients with schizophrenia.

## **Unterstützte Beschäftigung (UB)**

### **What is the measure?**

UB, introduced in 2009, is funding to be used to encourage greater equality for people with disabilities in the participation in working life (in accordance with UN conventions). Programs funded through UB provision must pursue the principle "first place, then train". UB programs follow an integrative approach to participation in working life, involving professional orientation and preparation, job placement and long-term stabilisation within employment

<sup>71</sup> BTZ-Hamburg "*Teilhabe am Arbeitsleben*" available at: [http://www.dgrw-online.de/files/icf\\_awk\\_3\\_dr\\_ibes.pdf](http://www.dgrw-online.de/files/icf_awk_3_dr_ibes.pdf)

<sup>72</sup> BAG-BTZ "*Kooperationen der BAG*" Available at: <http://bag-btz.de/kooperationspartner/index.html>

<sup>73</sup> BTZ Rhein-Neckar. Available at: <http://www.btz-rn.de>

<sup>74</sup> BTZ-Hamburg "*Teilhabe am Arbeitsleben*" available at: [http://www.dgrw-online.de/files/icf\\_awk\\_3\\_dr\\_ibes.pdf](http://www.dgrw-online.de/files/icf_awk_3_dr_ibes.pdf)



(LWL-Integrationsamt Westfalen, 2013). UB funding is for the development of supported employment programs, such as the Individual Placement and Support model.

The federal working group for supported employment providers, BAG UB, describes UB programs as supporting individual's choices, needs, abilities and potential, due to a belief in the importance of self-empowerment and participation. UB funding is always used for programs which support employment that takes place in the general labour market.

UB funding is primarily delivered through the Federal Employment Agency through a competitive tendering process. Various approved bodies (including IFD and BTZ).may apply for this funding to exercise supported employment programs. For example, in Cologne, Füngeling Router and BTZ Köln together won the competition to offer UB.

Those providing UB funded services will appoint job coaches before embarking on a two stage rehabilitation process.

- Qualification period, usually lasting up to two years, which can be extended by a further twelve months<sup>75</sup>: This consists of time to attain specific qualifications and undertaking on the job training in specific workplaces (*individuelle betriebliche Qualifizierung* or InBeQ) (Doose, 2012).
- Accompaniment into and during employment. There is no concrete limitation of time for this, though it is usually no more than six months. This is intended to support the employee's transition into general employment, with support most often provided by an IFD. A BAG UB survey showed that about 62 per cent of individuals having entered a UB program need further vocational support from an IFD.

The legal basis for UB funded programs is in §38a SGB IX.

### **Prevalence and Users**

The main target groups are school leavers with disabilities, adults who have developed a mental health condition during their working life and WfbM employees who want to move into the general labour market. Between May 2009 and October 2010 about 3,620 places in UB programs were provided, of which around 3,300 entered into InBeQ qualification measures. Among approximately 3,000 people in the InBeQ program in March 2012, 71 per cent had a learning disability, 15 per cent had a mental illness, and 9 per cent a physical or sensory impairment (Doose, 2012). The Federal Employment Agency data showed an increase in people with severe disabilities amongst UB participants between December 2009 and November 2013 – with 592 and 1,269 participants respectively.

It has been suggested that UB should be aimed at younger people – who may not be able to complete the occupational training options, but are deemed too capable to work in sheltered

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<sup>75</sup> Clients receive supported employment vocational training for two to three years, dependent on the requirements of the job (Doose, 2012; European Commission, 2011; Waldschmidt et al., 2009).

workshops (European Commission, 2011).

### **Movement in and of out the service, and between services**

Referrals into UB programs are made by the employment agencies or other rehabilitation funding agencies (Doose, 2012). According to the BAG UB 2011 survey 14.3 per cent of the young people participating came directly from school, 48.6 per cent were unemployed and 16.3 per cent came from a BvB (Bundesministerium für Arbeit und Soziales, 2012).

The Federal Employment Agency reported that for the 2,459 people exiting the UB between March 2012 and February 2013, 82 per cent were in employment, education or training after six months of the exit.<sup>76</sup>

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<sup>76</sup> Bundesagentur für Arbeit (2013) Austritte von Teilnehmern aus ausgewählten Instrumenten der Arbeitsmarktpolitik. [http://statistik.arbeitsagentur.de/Navigation/Statistik/Statistik-nach-Themen/Arbeitsmarktpolitische-Massnahmen/Eingliederungs-und-Verbleibsquote/Eingliederungs-und-Verbleibsquote-Nav.html?year\\_month=201203](http://statistik.arbeitsagentur.de/Navigation/Statistik/Statistik-nach-Themen/Arbeitsmarktpolitische-Massnahmen/Eingliederungs-und-Verbleibsquote/Eingliederungs-und-Verbleibsquote-Nav.html?year_month=201203)

## Glossary of German terms

*Arbeitsagentur* – Employment agency

*Arbeitsassistenz* – Work assistance

*Arbeitslosenhilfe* – Long-term unemployment benefit

*Arbeitsmarktrente* – Labour market pension

*Arbeitsplatzanpassungen* – Workplace adjustments

*Arbeitsplatzgestaltung* – Workplace engineering

*Ausgleichabgabe* – Employment quota levy

*Außenarbeitsplätze* – Outsourced work places

*Berufliche Rehabilitation* – Vocational rehabilitation

*Berufstrainingzentrum* (BTZ) – Vocational training centres

*Beschäftigungspflicht für Arbeitgeber* – Duty of employment quota

*Betriebliches Eingliederungsmanagement* (BEM) – Company integration management

*Bundesagentur für Arbeit* – National Employment Agency (<http://www.arbeitsagentur.de/>)

*Bundesarbeitsgemeinschaft Beruflicher Trainingszentrum* (BAG-BTZ) – Federal working group for vocational training centres (<http://bag-btz.de/>)

*Bundesarbeitsgemeinschaft für Rehabilitation* (BAR) – Federal working group for rehabilitation (<http://www.bar-frankfurt.de/>)

*Bundesarbeitsgemeinschaft für Unterstützte Beschäftigung* (BAG-UB) – Federal working group for supported employment (<http://www.bag-ub.de/>)

*Bundesministerium für Arbeit und Soziales* (BMAS) – Federal Ministry of Labour and Social Affairs (<http://www.bmas.de/>)

*Eingliederungshilfemaßnahmen* – Reintegration support measures

*Ergotherapie* – Occupational therapy

*gleichgestellt behinderter Mensch* – Equal to a disabled person

*Hilfesysteme* – Help systems

*Integrationfirmen / Integrationsprojekte* – Social firms

*Integrationsabteilungen* – Social firm (department within a larger company)

*Integrationsamt* – Office of securing the integration of disabled people in working life

*Integrationsberater/in* – Employment specialist

*Integrationsfachdienst (IFD)* – Integration Service

*Integrationsunternehmer* – Social firm (stand alone organisation)

*Krankenkassen* – Health insurance provider

*Land (Länder)* – State(s) of Federal Germany

*Medizinischer Dienst der Krankenkassen (MDK)* – Insurance company's medical services (

*Rehabilitationseinrichtungen für psychische Kranke und Behinderte (RPK)* – Rehabilitation institutions for people with mental conditions and disabilities

*Rentenversicherung* – Pension fund

*Schwerbehindertenausweis* – Disability pass

*Sozialgesetzbuch (SGB)* – Social Code

*Sozialhilfe* – Disability benefits

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