Employment Support for People with Psychosis

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10.1 Introduction

For most of us, having paid work is essential for well-being and financial security. But for many people who require some support to get into work, especially those with mental health problems, the right to employment is often not upheld. This chapter explores ways in which support with employment can be a part of a personal recovery journey for many more people than it is today. It focuses on interventions that can be provided by services to improve the support people with mental health conditions including psychosis receive to gain and retain employment.

10.2 Evidence About Employment for People with Psychosis

Research indicates that work is good for our physical and mental health (Waddell and Burton 2006), and many people who are using specialist mental health services want to work (Secker et al. 2001) and would like more help to get back into employment. Psychosis is considered as a severe mental illness and, hence compared to other mental illnesses, results in more disruption to employment status of individuals suffering from psychosis. The costs of lost employment due to mental health problems are substantial. In England in 2007, it was estimated that these amounted to nearly £20 billion (McCrone et al. 2008). There is persuasive evidence that being in employment is an important part of recovery for someone living with psychosis and indeed for most mental health conditions (Drake 2008). Gaining and retaining competitive employment has been demonstrated to achieve improved mental health outcomes and to sustain them over long periods. In a review of four

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models of psychiatric rehabilitation in people with psychosis, Baronet and Gerber (1998) concluded that being in employment was associated with an increase in independence, an improved sense of self-worth, and an improved family atmosphere. Similarly, Mueser et al. (1997) found that compared to those who were unemployed, participants who were in employment, after a period of 18 months, tended to have lower symptoms (particularly thought disorder), higher global assessment scores, better self-esteem, and more satisfaction with their finances and vocational services. Lysakar and Bell (1995) found a significant improvement in social skills after 17 weeks of job placement. Despite the evidence of its benefits, in the UK, the 2014 Care Quality Commission survey of community mental health service users found that 44 % of the 3,329 respondents said they would have liked support to find or keep a job but did not receive any (Care Quality Commission 2014): a finding that has been consistent each year this survey has taken place. Unemployment and mental health problems appear to have a causal link in both directions. People with mental health problems are much less likely than average to be in paid employment (Marwaha and Johnson 2004; Rinaldi et al. 2011, and people who have been unemployed for at least 6 months are more likely to develop depression or other mental health conditions (Paul and Moser 2009; Diette et al. 2012). McManus et al. (2012) found that one third of the new Jobseeker's Allowance claimants in the UK reported that their mental health deteriorated over a period of 4 months in this study, while those who entered work noted improved mental health. The employment rate of people with severe and enduring mental health problems is the lowest of all disability groups in England, at less than 10 %, and yet the research evidence on what works in supported employment for this group is particularly strong (Centre for Mental Health 2013). This finding is consistent with other countries like Australia (Frost et al. 2002). However some middle-income countries have shown high rates of employment for people with a severe mental illness. For example, Suresh et al. studied the work functioning of a cohort of 201 people who received community-based treatment in a rural south Indian community, and two thirds of individuals were employed at 3-year follow-up (Gudlavalleti et al. 2014). There may be lessons that can be shared in this area from developing countries.

10.3 Individual Placement and Support (IPS)

Research shows that the most effective method of supported employment for people with severe and enduring mental health problems is Individual Placement and Support (IPS). IPS was developed in the USA in the 1990s and has been replicated and successfully demonstrated in many other places including the UK, Norway, Denmark, Hong Kong, Canada, New Zealand, and Australia. A six-center randomized controlled trial (Burns et al. 2007) found that IPS was around twice as effective as the best alternative vocational rehabilitation service at achieving paid work outcomes in all sites. This study also revealed that people entering work did so more quickly and could sustain their employment for longer in the IPS services than in the alternatives. IPS has been found to be significantly better on all employment

outcome measures in people with first-episode psychosis than various control conditions, and patients receiving IPS gain significantly more jobs, earn significantly more money, and work longer (Crowther et al. 2001). To date there are at least 15 randomized controlled trials that demonstrate the efficacy of IPS (Drake and Bond 2011). Evidence on efficacy has emerged from randomized trials of IPS from many other countries, e.g., Canada (Latimer et al. 2006), Europe and the UK (Burns et al. 2007), Australia Killackey et al. (2008), The Netherlands (Michon et al. 2011), Switzerland (Hoffmann et al. 2012), and Hong Kong (Kin Wong et al. 2008). A briefer form of IPS (IPS–LITE) has also been tested and found to be equally effective to IPS (Burns et al. 2015).

As described below, IPS has *eight principles* and to be effective, supported employment services have to work faithfully to these principles:

1. *Competitive employment is the primary goal.*
   The fundamental assumption should be that paid employment (part-time or full-time) is a realistic goal for everyone who wants a job. Placement in education and training may provide a "stepping stone" for younger people and other forms of training might help some people, but the central goal of the service must always be paid employment.
2. *Everyone is eligible.*
   There are no "eligibility criteria" for entry into IPS programs beyond an expressed motivation to "give it a try." This should be irrespective of issues such as job readiness, symptoms, substance use, social skills, or a history of violent behavior. If a person believes paid employment is possible, and they receive the help they think they need, then their prospects are good. If they are subject to lengthy assessments to determine their "job readiness" and endless preparation of CVs and interview practice, then they will soon lose heart. People are "job ready" when they say they are and that is the time to start.
3. *Job search is consistent with individual preferences.*
   Working closely with someone's personal interests and experience significantly increases the chances of them enjoying and retaining a job. "*Do you want to work*?" and "*What do you want to do*?" are therefore the key – and indeed often the only – important assessment questions.
4. *Job search is rapid.*
   The job search should be started early (preferably within 1 month of referral to an employment specialist). A positive, "can-do" attitude should be cultivated in both staff and service users. Clear targets with dates for action need to be agreed and adhered to. Preparation should be concurrent with job search.
5. *Employment specialists and clinical teams work and are located together.*
   One of the most crucial aspects of the IPS approach is the quality of joint working between employment specialists and mental health teams. Employment specialists should be integrated, and preferably colocated, with clinical teams, irrespective of who employs them. They should actively take part in assessment meetings, influence referrals, and share in the decision-making process. The ideal scenario is that of a team wherein the employment specialist is part of the

team and is involved in developing with the client a care plan reflecting the personal preferences of the client. The employment specialist in collaboration with the client and the team is responsible for providing interventions that support employment as part of the client's recovery goals as, for example, in assertive community treatment teams (Schmidt et al. 1995). This may present a challenge to services that are more used to working separately, one after the other, i.e., "in a series," rather than "in parallel" together. It means that employment specialists must be central and equal members of the team, not peripheral "add-ons." In this way, the whole caseload of the clinical team is automatically the caseload of the employment specialist.

6. *Support is time unlimited and individualized to both the employer and employee.* The IPS approach makes getting a job the *start* of the process rather than the end point (it is "place then train," rather than "train then place"). Thus, support must bridge this crucial transition and continue in work for as long as is necessary. This means that individuals receive support that is based on their individual needs in relation to their jobs, skills, and preferences. Support is provided by a variety of ways by a variety of people including but not limited to employment specialists and clinicians (e.g., to help people to manage their mental health in the workplace) (Frydecka et al. 2015). Efforts should be made to include family members and close friends in the team to support people in their working lives, if they wish. Employment specialists may also provide support to the employer in line with the individual's wishes. Employment specialists should not require people to disclose their mental health problems to employers. Their role is to discuss the benefits and risks of disclosure and nondisclosure with the individual and support them in their decision.
7. *Welfare benefit counseling supports the person through the transition from benefits to work.*
   It is essential that employment specialists or clinicians offer assistance in obtaining individualized counseling services to understand the financial implications of starting work. This should include the process of managing the transition from welfare benefits to work and advice on in-work benefits such as Working Tax Credit, which is being replaced by Universal Credit. It is essential to have good relationships with specialist experts in the Jobcentre Plus and other welfare benefit agencies, such as Citizen's Advice.
8. *Jobs are developed with local employers.*
   This is a crucial aspect. The role of the employment specialists includes reaching out to local employers to identify potential jobs that fit well with an individual's skills, interests, and preferences.

10.4 Current Availability of IPS

The spread of IPS is still patchy, but it is growing. In 2009 only 2.1 % of US mental health clients had access to evidence-based vocational services (2009) but in 2011, IPS was offered by mental health agencies in at least 13 states. The Johnson & Johnson – Dartmouth Community Mental Health Program was created to further the dissemination of IPS by providing a structure for supporting implementation of

the various elements of IPS at the state level. This program has resulted in the formation of a national learning collaborative that supports the implementation of IPS services (Becker et al. 2011). In the UK, the Centre for Mental Health has recognized 14 sites as IPS Centers of Excellence, where fidelity to the evidence-based model, including excellent employer engagement strategies and effective partnership working between employment support workers and health professionals, is evident. But even in most of those high-performing areas, not all clinical teams have an assigned IPS worker, and therefore there are still large numbers of people who are denied access to an IPS service. The evidence base for IPS is predicated on trials within secondary care settings. There are, however, promising examples of the success of using the IPS model with primary care mental health teams. In the UK, there are IPS workers in some IAPT (Improving Access to Psychological Therapy) services, including Wolverhampton Healthy Minds and Wellbeing Service. Extending and adapting IPS to primary care for people with common mental health problems was among the major recommendations of a government-commissioned report by RAND Europe (van Stolk et al. 2014) which is, at the time of this writing, being piloted in four areas of England. There is also evidence from a pilot scheme run by the Central and North West London NHS Foundation Trust that IPS can be successfully adapted to people with drug or alcohol addictions (Centre for Mental Health 2014). In addition, another pilot project on IPS is currently under way in the West Midlands (UK) that intends to provide employment support to people with mental health problems who are leaving prison.

10.5 The Impact of Employment: An Example from Practice

From the narrative accounts of people's journeys through supported employment in Central and North West London, Miller et al. (2014) have identified the benefits of being in work and the unique path each person takes to gain and retain employment. One service user described his journey, which began with him wanting to work and contacting an employment specialist (ES) as: "When I met my ES, she discussed what my motivations were and whether I wanted to work. I felt at last there was someone to help…" (Miller et al. 2014). He describes a process that began with rapid job search based on his interests and skills and which included help in preparing for interviews. The ES then *proactively* sought a suitable role for him and offered both him and his employer ongoing advice and support. "I am now in part time work as a cleaner. I cannot believe I have finally got a job. It has changed my life. I feel happy within myself, the bad thoughts from my head have disappeared" (Miller et al. 2014).

10.6 Barriers to Employment and Suggestions to Address the Barriers

There are numerous barriers to people with mental health problems getting paid work. Limited availability of IPS is a major barrier, but there are other obstacles, as discussed below.

10.6.1 Stigma and Discrimination

The fear of being stigmatized and discriminated against either in the process of job seeking or within the employment itself is common among people with mental health problems. A study of 949 people with mental health problems found that 53 % reported some experience of discrimination. The areas in which this discrimination most frequently occurred included employment, housing, and criminal justice system interactions (Corrigan et al. 2003). A Mental Health Foundation study looking at return to work after sickness absence found that almost half of employees off sick with physical health problems also experienced mild to moderate depression, but were more worried about telling their employer about their mental health issues than about their cancer or heart disease Loughborough University/Mental Health Foundation 2009). Danson and Gilmore (2009) found that employers are wary of employing people with a health condition. They found that while employers had sympathy toward people with disabilities, mental health problems, or those who had recovered from serious illness, they were also concerned that, as employees, their disability or illness might lead to future difficulties and financial pressures for the business.

The continuing existence of stigmatizing attitudes toward people with a mental illness remains a significant barrier for people seeking work. The *Time to Change* campaign in England, which has run since 2007, is aimed at both the general population and at specific target groups, such as employers and health professionals. The campaign has made use of social marketing, advertising campaigns, and events designed to deliver social contact between people with experience of mental health problems and various target groups. Between 2006 and 2010, *Time to Change* measured encouraging reductions in discrimination in five areas of life, including finding a job and keeping a job (Corker et al. 2013). Henderson et al. (2013) found that employers' attitudes toward potential employees with mental health problems improved during *Time to Change*. There are similar campaigns and initiatives in a number of other states, including Scotland, Australia, and New Zealand. These need to be sustained in order to create the lasting change in attitudes and improvements in knowledge that are vital to reduce experiences of discrimination over time. Whereas Biggs et al. (2010) had noted that employers were concerned that people with mental health conditions would need additional supervision and would be less likely to use initiative or to deal confidently and appropriately with the public, Henderson et al. (2013) found employers had become less likely to perceive people with mental health problems as a risk with respect to their reliability, working directly with customers, or in terms of their colleagues' reactions to them. In contrast to the above examples of stigma and discrimination, many rural areas in low- and middle-income countries seem to provide a community that is accepting of individuals with psychosis and provide them a variety of opportunities to engage in meaningful employment (Yang et al. 2013).

10.6.2 Low Expectations

When people with mental health conditions experience discrimination and therefore difficulty in finding and keeping work, it can reduce expectations that future

employment experiences will be happier and more successful. Identification with the personal experiences of others may also spread a feeling of pessimism about the real possibility of work among job seekers with mental health problems. Employers with no direct experience of employing someone with a mental health condition themselves may also be influenced by the experiences of other employers, which, if negatively described, can dissuade them from giving a chance to anyone with a mental illness.

Low expectations can be reinforced by health professionals. Many people with mental health conditions report that their doctor, psychiatrist, or nurse saw their illness as a genuine barrier to employment (Marwaha et al. 2009). Bevan et al. (2013) found that clinicians tend to believe that people with schizophrenia who want to work would probably be capable only of noncompetitive work (i.e., voluntary or sheltered work). Yet suggesting that people put their employment aspirations "on the back burner" during months or even years of experiencing a range of therapies, drug treatments, and social support (through day service attendance or participation in vocational training or sheltered work units) has been shown to result not only in lower levels of employment, which would be expected, but also in higher levels of psychiatric illness demonstrated by more frequent and longer hospital admissions over time (Bush et al. 2009). Even when mental health professionals do believe that the people they are supporting are capable of work, this does not necessarily translate into encouragement to find work or referrals to employment services. For example, a study of the employment status of clients using a London community mental health service found that while mental health staff rated 18.9 % of their clients as capable of open-market employment, the percentage actually in work was only 5.5 % (Lloyd-Evans et al. 2012). In the area under review, mental health service users did not have access to a supported employment service providing high-fidelity Individual Placement and Support, although some other forms of employment support were available including voluntary sector employment services and Jobcentre Plus disability employment advisors.

Health and social care staff have regular opportunities to discuss employment with people using their services. It is vital that these opportunities are taken and that a person's motivation and sense of hope are encouraged rather than dampened in the interactions they have with professionals.

10.7 Government Policy

In the UK, welfare benefit caps and the changes to benefit rules in recent times mean that anyone with a mental health condition who is unemployed and claiming the benefits is highly likely to increase their income by entering paid employment, even where this is part-time. Government policies over many years have dis-incentivized a life on benefits and vilified anyone considered to be capable of work for remaining unemployed. Patrick (2012) discusses the "determined focus" of the three main political parties on work as the central duty of all "good" citizens.

Universal Credit, introduced in 2013, was designed to simplify the benefits system by replacing the six main out-of-work benefits and Working Tax Credit.

The earnings disregard, changed to an annual amount, depending on personal circumstances, tapering the amount of Universal Credit received as earnings increase. Disability Living Allowance, a benefit payable to people with mobility and care needs, regardless of employment status or income, was replaced by Personal Independence Payment (PIP), with most existing claimants likely to be reassessed in 2015. In the UK, anyone found fit for work through the Work Capability Assessment or those put into the Work-Related Activity Group (WRAG) of Employment and Support Allowance and people who have claimed Jobseeker's Allowance for 3 months are usually mandated to the Work Programme. People with additional needs, including people in the Support Group of Employment and Support Allowance, meanwhile, are able to engage voluntarily with the Work Programme or to use the Work Choice, the specialist employment program for disabled people. The Work Programme gives providers wide scope to find their own creative and individualized support options for people with any disability or need which may place them at a disadvantage in the labor market. Employment support is funded through staged payments which the Work Programme provider draws down at engagement, job entry, and successive points of job retention. A person previously claiming disability-related benefits such as Employment and Support Allowance (ESA) attracts a higher rate of payment to the provider when they become employed and maintains that employment, than a person who had been claiming Jobseeker's Allowance. Unfortunately the figures to date for the Work Programme describe the lack of success that providers have had in helping people on disability benefits into work (House of Commons Committee of Public Accounts 2013). Critics of the Work Programme say that people with additional support needs are not receiving the individualized support package they require and that easier-to-help clients are being "creamed" and helped quickly and successfully into work, while those who need more intensive or specialist support are being "parked" with very little expectation that they will ever find work.

Work Choice, the DWP program designed for people with additional needs, has been able to support only 650 people with a severe mental illness during the 42 months from April 2011 to September 2014. In this program although an encouraging 37 % of these people have achieved a job outcome, this is only 240 across the whole country (Department for Work and Pensions 2014). This figure looks all the more paltry when compared with the 403 people with severe and enduring mental health problems who could be supported into jobs by just one IPS service (Southdown, in Sussex) in the 20 months between April 2011 and November 2012 (Centre for Mental Health 2012). Unfortunately the DWP schemes are not succeeding in improving the current levels of employment of people with mental health conditions nor are they able to address the huge inequality in employment rates between people with mental health problems and those with other disabilities, other health conditions, or no disability. Thus a better targeted and evidence-based approach to supported employment is indeed necessary to meet the needs of this group of job seekers.

10.8 Funding for Supported Employment

In some locations, mainstream health and social care funding has established IPS services. However, provision is being cut back where budget reductions make this necessary, and in some areas, supported employment is only funded by short-term grants to voluntary sector services. The local need for IPS services should be recognized by Clinical Commissioning Groups and local authorities because employment for people with mental health problems is an expected outcome in the NHS, public health, and adult social care outcomes frameworks. Usually local authority social care services prioritize the care needs of people, including those with mental health problems, according to the criteria of the Fair Access to Care Services (FACS) framework. Someone who, without intervention, would not sustain their involvement in many aspects of work, education, or learning is considered to have a substantial social care need in this area and is likely to be eligible for support.

A possible option for funding the IPS where there is currently no established service could be through a personal budget. The Community Care (Direct Payments) Act 1996 gave local authorities the power to make direct cash payments to individuals instead of providing the community care services they have assessed those individuals as needing. People who receive the payments use the money for the purchase of support, services, or equipment which will meet the assessed need. Many local areas have trialed the use of Personal Health Budgets which identify, through a similar process, the amount of funding available to be spent on an intervention for a healthcare need. A Personal Health Budget is the provision of this funding to the individual to use in a way which suits their personal circumstances and aspirations better than the standard or "mainstream" service on offer. Personal budgets through health or social care (or possibly a pooled health *and* care budget) could enable an individual to buy the services of an IPS employment specialist with a proven track record in successful work outcomes for people with mental health problems. However this model may require additional funding to become viable. At present there are few areas where personal budgets for employment support are being used or indeed could be used. This may be because either there are no local IPS services to purchase or because the costs would have to be set at a relatively high level per person to cover the overheads of keeping the service viable, i.e., running with a minimum number of staff, and the amount of personal budget awarded may not be sufficient to cover the cost of employment support (which may be needed for at least a year).

Craig et al. (2014) have published findings from their study of local authority and NHS spending on supported employment. They asked a specific question about personal budgets, i.e., whether people are allowed to spend their personal budgets on employment support and, if so, whether they do. In this study, 76 % of respondents stated that people are allowed to use personal budgets for employment support, 12 % responded that they were not, and 11 % did not respond. Only 28 % of respondents actually knew that people were using their personal budgets for employment support, 17 % knew that they were not, and 35 % did not know either way. The

remainder did not respond. For mental health service users, the breakdown of personal budget spend on employment support was as below:

- Specific work preparation activity in day services: 36 %
- Support into paid work: 30 %
- Support into self-employment or microenterprise: 8 %
- College courses: 7 %
- Volunteering with an end focus on paid work: 7 %
- Support into unpaid work: 2 %
- Not specified: 10 %

10.9 Access to Work

The Access to Work scheme provides government funding to employers to make "reasonable adjustments" at work to enable them to employ a disabled person. The Sayce Report *Getting In*, *Staying In and Getting On* (Sayce 2011) reviewed some of the specialist provision aiming to increase the employability of disabled people which was available to them at the time. The report noted that Access to Work was underused, largely unknown, and yet had the potential to provide a tailored package of support which could enable people with disabilities, including those with mental health needs, to overcome their own barriers to work. Similarly, Biggs et al. (2010) investigated employers' attitudes toward making reasonable adjustments to support employees with mental health needs. They commented that Access to Work could have been used more effectively for transport to and within work since they found that a significant number of employers stated that they would be prepared to allow flexible working hours, job sharing, and temporary assignment of duties to other colleagues and to accommodate sick leave, but few were prepared to provide or pay for transport to get to work, to get to meetings, or to visit clients.

In recognition of the different needs of people with a mental health condition and the disproportionately low take-up of Access to Work by this group, the government tendered a contract to provide a specific Mental Health Access to Work service, for which Remploy was the successful bidder, and the service became operational in 2012. The Remploy service is able to meet needs such as:

(i) Advice and personal support to manage a mental health condition at work
(ii) Mediation with employers regarding reasonable adjustments and human resource processes
(iii) Information about ongoing sources of support
(iv) Signposting to other services

The support generally takes the form of a number of face-to-face or telephone support meetings over a period of time, not exceeding 26 weeks. At present, just 4 % of Access to Work funding is used to support people with mental health conditions in work (Work and Pensions Committee 2014).

10.10 Conclusion

For many people, having a psychosis means losing work and multiple individual, family, and societal barriers to regaining employment. The costs of lost employment due to mental health problems are enormous. The good news is that attitudes are beginning to change with professionals recognizing that competitive work is possible and beneficial for people with psychosis and health systems and governments trying to create programs to help people to find employment. However, the provision of effective support for people with a range of mental health problems to stay in work or get a new job is patchy and burdened by significant limitation of available resources. What we need is interdisciplinary and concerted action from government, health services, local authorities, and employment services to offer support that works, building on the evidence we have and exploring opportunities for further learning, for people with mental health problems who want to work.

10.11 More Information

More information on supporting people with mental health problems into employment is available at www.centreformentalhealth.org.uk.

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