

Young people who have had a mental illness face significant barriers to both gaining and maintaining employment. A study, using a qualitative design and consisting of two focus groups, was conducted to identify the issues experienced by young people diagnosed with psychosis wanting to gain employment. The participants were 10 registered clients of an Australian mental health service that had a specialised early psychosis programme. The themes identified in this study concerned loss, low self-confidence and self-esteem, stigma, treatment issues, the need for support, and difficulties in identifying and achieving goals. Further research is warranted to gain a greater understanding of the type of programme that would best assist young people to gain and maintain employment.

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# Work Issues for Young People with Psychosis: Barriers to Employment

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## Introduction

Research indicates that there are a significant number of young people who are at risk of experiencing continuing labour market disadvantage. These young people are those who are unemployed or employed part time and are not in education. Many young people who experience mental health disorders fall into this category. As a result of the onset and progression of the illness, the young person's secondary and tertiary education are most likely to have been interrupted or to have come to an end. Too often the young person's ability to gain and sustain employment is affected by relapse, the side effects of medication and the continuing symptoms of his or her illness. Most importantly, the skills central to a successful job search (such as communication skills, social skills, decision making and time management, and the ability to motivate self or demonstrate initiative) are severely diminished.

Occupational therapists recognise that involvement in paid employment is a significant life occupation for many people and is a realistic goal for people who have experienced a mental health disorder (Lloyd and Bassett 1997). There are several benefits of employment in the open labour market for many people with a psychiatric disability. These include economic independence, personal satisfaction, daily stimulation, social interaction and a widening of leisure and recreational opportunities (Commonwealth of Australia 1993).

Despite the recognition of the benefits of open employment, people with a psychiatric disability experience a number of barriers in accessing paid employment. Lack of access to vocational and educational training, the debilitating effects of psychiatric illness, job design, work environment, negative employer and community attitudes, and little assistance following gaining employment are the barriers most frequently noted

by people who experience a psychiatric disability (Commonwealth of Australia 1993).

McClelland and Macdonald (1999) recognised the need for more information to be gathered about labour market outcomes for people with a disability. The present study examined the issues that young adults with psychosis identified as having an impact on their ability to gain and maintain employment in the open labour market.

## Literature review

### Young adulthood

The period of young adulthood is characterised by redefining one's self-image through the questioning of adult roles and societal values, increased independence from the family, increased interdependence with peers, experimentation, generating new interests and making personal choices (Blakeney 1985, Sholle-Martin 1987). For many, it is a time of making decisions that lay the foundations for a stable and secure future, such as finalising their secondary and initial tertiary education, moving out of the parental home, forming significant personal relationships and beginning a family. Securing full-time employment is identified as a crucial step for young people to achieve success in making this transition to independent adults (Sweet 1998).

### Employment opportunities

It is widely recognised in the literature that young people aged 15 to 24 years experience significant difficulties in obtaining secure and continuing employment that offers opportunities for career development and financial independence. Drummond (1999) identified five issues that had a major influence on a young person's employment opportunities: stable, affordable housing, the development



of life skills, networks, good health and affordable, non-judgemental child care for young mothers could make the difference between getting a job and not getting a job for many young people. However, the literature that addresses the issue of youth unemployment tends not to address the particular needs of young people with a disability. Instead, it primarily addresses the labour market disadvantage experienced by young people and the impact of unemployment on the health of young people (Kieselbach 1988, Winefield et al 1993).

### **Barriers to employment**

The constraints within mental health services have been identified as restructuring of the mental health system, mental health staff's low vocational expectations for employment and negative staff attitudes towards employment (Graffam and Naccarella 1997). Community-related factors, such as labour market opportunities, unemployment rates and availability of community services (for example, housing, public transport and recreational facilities), are also identified as having an impact on the employment opportunities of people with a psychiatric disability (Graffam and Naccarella 1995, 1997).

### **Vocational outcomes**

Anthony (1994) identified four characteristics contributing positively to the ability of a person experiencing a mental illness to obtain and maintain employment: work readiness, work attitudes, interpersonal relations and work quality. Issues identified as having a negative impact on employment outcomes included multiple impairments (cognitive, perceptual, affective and interpersonal), decreased life experiences, associated substance abuse, the episodic nature of the illness, obstacles within the service delivery system and the negative symptoms of the illness being confused with lack of motivation (Department of Education Washington 1993). Factors identified as not predictive of employment outcomes were employment history, work experience, age, and number and length of hospitalisations (Anthony 1994).

### **Psychosis**

Psychotic illnesses, such as schizophrenia, schizophreniform psychosis and drug-induced psychosis, usually have their onset in late adolescence or young adulthood (McGorry 1992). Experiencing psychosis in young adulthood has a devastating impact on a young person's life roles, educational and vocational goals, social relationships and contributions to the community (Yung and McGorry 1996, McGorry and Edwards 1997). For young people experiencing a mental disorder, the opportunities to achieve their vocational goals and make career choices are interrupted by periods of hospitalisation and recovery from their illness and the managing of both the positive and the negative symptoms of their illness. As a result, many young people with a mental disorder present with poor self-esteem and a lack of confidence in their abilities to make decisions and achieve their personal and vocational goals.

### **Occupational therapy**

A professional group that is well aware of the importance of meaningful occupation is occupational therapy. Occupational therapists recognise the devastating effects that a psychotic illness can have for a young person owing to the interruption caused in the development of his or her persona. While there is not an abundance of literature that specifically addresses employment and young people with a mental disorder (Skate and Ryan 1996), occupational therapists are beginning to develop programmes that target the issue in this particular population (Lloyd and Bassett 1997, Parlato et al 1999). General mental health literature, on the other hand, primarily focuses on identifying employment issues for people with a mental illness, regardless of age or developmental stage (Marrone et al 1995, Dowsett and Ashton 1996, Sanders et al 1996).

### **Statement of the issue**

What appears evident from the review of the literature is that young people face significant challenges in gaining and maintaining employment. There has been little research that specifically identifies the issues faced by young people experiencing psychosis who want to join or re-join the labour force. It is hoped that a greater understanding of these issues will assist occupational therapists to develop programmes that address the issues identified as being important for both gaining and maintaining open paid employment.

### **Aim of study**

The aim of the research project was to increase the understanding of the issues faced by young people experiencing psychosis who wanted to gain or maintain employment.

### **Method**

#### **Research design**

In order to explore the issues faced by young people experiencing psychosis in regard to employment opportunities, it was decided to adopt a qualitative approach using two focus groups. This process was selected because it would allow the researcher to gain an understanding of a range of opinions and attitudes, and the reasons behind these attitudes, through the use of open-ended questions.

#### **Participants**

The participants consisted of young people who had been diagnosed with a psychotic disorder. They were registered clients of the Gold Coast Integrated Mental Health Service (IMHS). This health district was chosen as the site for the research because it is one of the few mental health services in Queensland that has a specialised early psychosis programme, known as the Young Occupations Unlimited (YOU) programme (Parlato et al 1999). This programme is

for people between 18 and 25 years, recently diagnosed with psychosis, who have the goal of undertaking further education, training or work.

The members of the programme over a 2½-year period (n=35) were contacted and the purpose of the research explained to them. They were asked if they would like to participate in the research. They were provided with a fact sheet outlining the research. Informed consent was obtained from the participants prior to their participation.

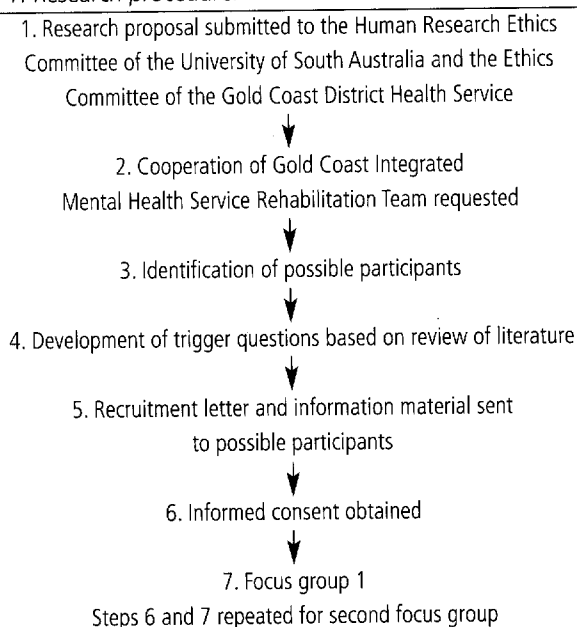
## Procedure

The Human Research Ethics Committee of the University of South Australia and the Ethics Committee of the Gold Coast District Health Service gave ethical approval for this study.

The participants were allocated to one of the two focus groups on the basis of their involvement in the YOU programme. One focus group consisted of the young people who were then attending the YOU programme and the other focus group consisted of the young people who had previously attended the YOU programme.

The two focus groups were conducted by the first author and a facilitator of the YOU programme. The same process was followed in both groups. The groups were audiotaped and lasted for about 90 minutes. The participants were asked questions that focused on the experience of psychosis and its impact on their ability to seek and maintain employment, their employment goals, and the types of services that they believed would assist them. These trigger questions were developed to guide the discussion (see Appendix 1). The research procedure is shown in Fig. 1.

Fig. 1. Research procedure.



## Data analysis

The data were retrieved through verbatim transcripts of the audiotapes. The transcripts were reviewed by an independent reviewer. Similar responses and meanings were grouped together and categorised to form a description of the participants' experiences. The data were analysed using the procedure suggested by Hawe et al (1990). This

procedure involved, first, organising the data following the transcription of the tapes. The second step involved shaping of the data, that is, organising the data into themes or patterns. The third and final step involved the interpretation or explanation of the data.

## Findings

Ten members of the programme agreed to participate in the research. All participants were able to read and write English and were motivated to find paid employment. The participants were aged between 18 and 28 years, were single and male, had an Anglo-Saxon background, and were in receipt of welfare benefits. There were five participants in each of the two focus groups.

To illustrate the themes, direct quotes made by the participants are included. Since there were more similarities than differences in the themes between the two groups, the results have been pooled for ease of presentation of the data.

## Themes

### Loss

The experience of mental illness resulting in loss of youth, relationships, abilities and job prospects was discussed. The issue of loss was also discussed in relation to loss of goals, self-esteem and self-confidence and changes to body shape as a result of medication. In discussing their experiences of being a young person who had experienced a mental illness, the participants reflected upon how they had tried to push their friends away because they had been in hospital and the loneliness that had resulted. The participants felt that it was hard for them to talk to people because they had very little going for them. Low self-worth and low self-esteem emerged strongly, as reflected in the comment: 'It is a vicious circle, cause you don't have any work and you don't bring in an income and it gives you no self-esteem and then you don't want to get up and go get a job.' The impact that a mental illness had on employment goals was reflected in this comment: 'Since what has happened, and it just overwhelmed me because I did have my dreams.'

### Stigma

Stigma was discussed in relation to the issue of disclosure to potential employers in an interview setting, to employers and work colleagues and in personal relationships. The issue of disclosure in relation to job interviews and job applications generally was also discussed. There were mixed opinions on the issue of disclosure. Some participants commented on the employer's right to know while other participants would have preferred not to discuss the issue of mental illness until after they had obtained the job, if at all. As one participant stated: 'I would rather get the job, a foot in the door, to prove that I can do the job then you know ...?' Another young man commented: 'It is just like in a relationship, you don't just go up and tell the girl, "You know, I'm schizophrenic".'

When discussing their personal relationships, the participants felt that once people knew that they had been diagnosed with a mental illness, they would not want to know them because of the stigma attached to mental illness.

### **Treatment issues**

The theme of treatment was discussed in relation to admissions to hospital, relationships with staff and the side effects of medication. The participants who commented on treatment within the mental health setting expressed negativity in relation to their experiences. One participant stated: 'You're a guinea pig ... they don't sit down and talk to you, it's just whacked straight on the heavy drugs.' It was felt that it was not right to have to go into hospital and that being there was not a pleasant experience, as was reflected in the comment: 'Everyday was hell just looking at the air vent above and I just didn't like it at all.'

The participants commented on the lack of choice that they experienced when being admitted to hospital and the difficulties they had in moving on from the experience. Some concerns were raised about the need to be involved in continuing treatment. There were also comments on the negative effects of medication, especially in relation to motivation and tiredness and how difficult it was to get out of bed.

### **Symptom management**

The participants discussed the impact of their illness on their ability to gain and maintain employment in general terms. From their comments, they also appeared to lack strategies to manage symptoms and issues that might arise in the workplace. One participant commented on his inability to manage his feelings of frustration in a work setting, which had contributed to his losing a previous job. Another participant spoke about the stress associated with hearing voices and his inability to 'handle work under that type of stress'. The participants did not identify any strategies, services or programmes that would assist them to manage better the issues raised.

### **Life goals**

The participants discussed the impact that mental illness had upon their life goals. They recognised that their personal goals had changed and expressed uncertainty about their ability to achieve future goals. They appeared to have difficulty in identifying tangible goals and articulating a plan to achieve these. One participant noted that a past challenge for him had been the amount of time during the day. He stated: 'I remember when I used to sit around and just wait for time to pass so I could just eat my dinner and go to bed.' They discussed how hard it had been for them to identify their life goals or the changes to these goals since becoming unwell. One young man stated: 'I still want my dreams and goals. Dunno, it's confusing, going about achieving them.'

### **Need for support**

In response to the question that asked participants to identify services or resources that would assist them to

achieve their work goals, the discussion focused on programmes that assisted in the development of time management, stress management and problem-solving skills and programmes that addressed self-confidence. The participants also identified the need for programmes that assisted them to prepare for work, especially managing the lifestyle change from not working to being employed. A participant commented: 'When you are not working you're used to not having much production and then suddenly being put into a position where you have to perform eight or nine hours a day. You are going to find it difficult because it is a shock to the system...'

## **Discussion**

The aim of the research project was to increase the understanding of the issues faced by young people experiencing psychosis who wanted to gain or maintain employment. The study highlighted that the issues identified by the young people as having an impact on their employment opportunities were many and complex. Primarily, the issues centred on loss resulting in low self-confidence and self-esteem, stigma and disclosure, treatment and symptom management, difficulties in identifying and achieving goals and a need for continuing support.

### **Loss**

The issue of decreased self-confidence and little self-worth was a significant concern for the participants involved in this study. Experiencing psychosis during the period of young adulthood has a significant impact on the young person's vocational, social and educational goals and plans (Yung and McGorry 1996, McGorry and Edwards 1997). Central to people's ability to secure employment is their belief in themselves, the ability to articulate their strengths and identify their skills and sell these to prospective employers, and to continue with the job search despite experiencing rejection. The comments of many of the participants indicated that they would experience extreme difficulties in doing all this. These young men identified the need to access programmes that assisted them to enhance their skills in the areas of time management, stress management, and ability to manage change and increase their self-confidence.

### **Stigma and disclosure**

The issues of stigma and employer and community attitudes towards mental illness had an impact on the participants' experience of employment. It has been noted that negative employer and community attitudes are a significant barrier to employment. These attitudes not only lead to reluctance to hire a person with a psychiatric disability but may also affect the level of job in which the person is placed, the opportunities for advancement, and the risk of being dismissed in an economic downturn (Commonwealth of Australia 1993). It has further been suggested that additional problems are created for those employees who choose to

hide their illness from employers; for example, the stress may exacerbate the likelihood of the illness recurring (Commonwealth of Australia 1993).

### **Treatment-related issues**

The debilitating effects of psychiatric illness and treatments have been identified as one of a number of barriers to employment (Commonwealth of Australia 1993). The participants in this study noted the effects of medication and side effects as an issue for them, particularly in relation to their feeling that they did not have enough energy to attempt job seeking. It would appear essential for people with a mental illness to be given more information about their medications and side effects and the strategies for managing symptoms. In addition, it would seem that it is important to discuss with people the necessity for allowing some time for recovery before looking for work or returning to work.

It was interesting to note that, through their comments, the participants seemed to see their involvement with the mental health service as being primarily responsible for their employment status. The restructuring of mental health services, mental health staff's low vocational expectations and negative attitudes towards employment have been identified as barriers faced by people experiencing a mental illness who want to undertake paid employment (Graffam and Naccarella 1997). This is an issue that needs further attention by mental health workers.

### **Goals**

All the participants involved in the study expressed a motivation to work. However, many of them identified vague employment goals. It is noted that securing employment, preferably full time, is central to increasing independence and assuming the responsibilities of young adults (Sweet 1998). Many of the young men also experienced difficulties in identifying how they were to achieve their goals, with little understanding of community resources and services available to provide vocational or employment assistance. There was little discussion on issues of employment opportunities in the labour market, access to employment services or education and training facilities. These are factors identified as contributing towards labour market disadvantage in young people (Spierings 1999). Drummond (1999) noted that young people are at times critical of careers advice and feel that they are not given enough information in this regard.

### **Labour market disadvantage**

McClelland and Macdonald (1999) recognised the need for more information to be gathered pertaining to labour market outcomes for people with a disability. The young people involved with this study were at a significant risk of experiencing labour market disadvantage, as identified by Marks and Fleming (1998). Further factors that also had an impact on positive employment outcomes relevant to the participants were the episodic nature of the illness, associated substance abuse, decreased life experiences and

experiencing continuing negative symptoms (Department of Education Washington 1993).

All the participants had a sporadic work history, with those who were working doing so part time or on a casual basis. Many of the participants had not been employed since becoming unwell or, if they had been working, had lost the job after a short period of time as a result of their illness. Many of the participants stated that they had left school at an early age and had not undertaken further study since then.

The literature indicates that a frequently mentioned barrier to employment is the lack of access to vocational and educational training for people with a mental illness (Commonwealth of Australia 1993). For those people who manage to obtain or regain employment, there is generally little assistance or back-up to support this major adjustment. It is necessary for mental health professionals to look at ways in which this support could be provided.

### **Occupational therapy**

It is evident from the comments of these young people that they experienced significant difficulties in choosing, performing and organising occupations that they found meaningful. Occupations are defined as everything people do to occupy themselves, including looking after themselves, enjoying life and contributing to their community (Townsend 1999). Occupational therapists have the potential to play an important role in service development for young people wishing to undertake further education, training or work. Synder et al (1998) illustrated the role of occupational therapists in the development of programmes that provide the opportunity for young people to make occupational choices that are healthy, productive and socially acceptable.

The principles underpinning the Model of Human Occupation allow occupational therapists to develop programmes that address the many needs of young people experiencing psychosis who want to obtain employment. This model recognises the relationship between a person's environment (physical, social and cultural) and the individual's ability to make decisions, believe in himself or herself, identify interests and personal values (volition), organise behaviour into routines (habituation) and perform the skills essential to the undertaking of daily occupations (performance) (Kielhofner 1992).

Occupational therapists are encouraged to develop programmes that provide practical opportunities for the young person to do this. In a supportive environment, the focus is on establishing a working partnership between therapist and client. Young people require the opportunity to develop or enhance their skills in the areas of communication, self-confidence, time management and goal setting. Programmes need to provide information and resources that assist these young people to gain a greater understanding of their illness and also strategies to manage their symptoms, allowing them better to minimise the impact of these on their employment goals. Importantly, programmes need to address the issues of loss and grief

experienced by these young people as a result of becoming unwell. The issue of loss was reflected in the comments of many of the participants.

## Conclusion

This study had a number of limitations, namely that the sample size was small, the participants were all male and were all from one health district, and one facilitator of the programme had previous involvement with all the participants through the mental health rehabilitation programmes. These factors may limit the generalisability of the results. However, the study indicated that the young participants did not identify labour market opportunities or a lack of them as the most significant issue influencing their ability to gain employment. There appeared to be a number of barriers identified by the young participants that had an impact on their ability to achieve their goal of employment. The participants focused primarily on issues related to personal losses, low self-esteem, a lack of direction and the experience of being unwell.

It is suggested that occupational therapists have an important role to play in the development of programmes designed to assist young people experiencing psychosis to achieve their vocational goals. Further research is warranted to gain a greater understanding of the impact that mental illness has on young people both seeking and maintaining open employment. It is recommended that further research include a larger sample size, participants from different geographical regions and both male and female participants. Topics for inquiry could include whether the programmes that address the skills required for work increase such young people's ability to seek and obtain employment and whether the programmes that focus on strategies to manage symptoms and workplace issues increase the likelihood of their maintaining employment. Further research is also warranted to explore any similarities or differences between the responses of young people with psychosis and unemployed young people who have not experienced psychosis.

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## Appendix 1. Trigger questions to guide the discussion

1. What is it like being a young person who has experienced mental illness?
2. In what ways, if at all, have your employment or job goals changed since becoming unwell?
3. What issues do you believe have an impact on your ability to keep and find work?
4. What services or assistance do you believe would assist you to gain or maintain employment?
5. Do you believe that your illness will have any impact on your ability to find or keep work?

# Call for Papers: Professional and Fieldwork Education

There will be a special issue of the *British Journal of Occupational Therapy* in late 2001 or early 2002 focusing on new initiatives in professional and fieldwork education. There are many reasons for these timely topics.

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Fieldwork education is changing rapidly and is following new models, and even the name 'fieldwork' is being denounced as coming from another era. The concept of the clinician/manager/educator/researcher, in touch with the changing pace on several fronts, is being held up as a new way of 'being' - the advanced practitioner.

Contributions are invited for this special issue of *BJOT* from all areas of practice on:

- Changing education with changing health care needs
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- Embedding clinical reasoning, continuing professional development and reflection in higher education programmes and fieldwork settings

- Learning practical skills alongside experiential work that is facilitated by a practitioner/educator
- Examining personal values and beliefs that make the therapist/educator who he or she is.



Susan Ryan

Potential authors wishing to discuss ideas can contact Susan Ryan, University of East London, on sryan31865@aol.com or Upma Barnett, *BJOT*, on upma.barnett@cot.co.uk (Tel. 020 7450 2338). Articles must be marked for this special issue and should be submitted by the end of May 2001. They will

undergo the normal referee procedure (please see the *BJOT* author's guide, which was last published in July 2000).

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