



# Participation in work: A human rights issue for people with psychiatric disabilities

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ABSTRACT

The article will endeavour to situate discrimination against disabled people in the world of work as a human rights issue. An argument will be made for occupational therapists to give more attention to recent developments in the literature, policies and legislation in order to develop services that will best promote the participation of people with disability in work. Recommendations for service models will be made, each based on a case study that was developed using an interpretive biography research design.

**Key words:** supported employment, vocational rehabilitation, psychiatric disability, human rights

## Introduction

“Widespread ignorance, fear and stereotypes cause people with disabilities to be unfairly discriminated against in society and in employment. As a result, people with disabilities experience high unemployment levels and, in the workplace, often remain in low status jobs and earn lower than average remuneration”<sup>1</sup> (p4).

Work has always been a major focus of occupational therapy, yet, very few programmes are in place to facilitate the participation of disabled people in the world of work. Occupational therapy services within the domain of work fell within one of three foci (1) work assessment (often to determine eligibility for a disability grant), (2) vocational rehabilitation or work hardening programmes that rely on simulated work or (3) protected or sheltered work. Thus, very few programmes have the expressed outcome of integrating disabled people in the open labour market<sup>a</sup>. The argument will be made here that occupational therapists should make ‘participation in work’ a first priority for focus and development. Reprioritisation of work is justified by the recognition that:

- it is a human rights issue,
- occupational therapy research and philosophy has shown it to be a basic human need and
- for most people, it is the only viable source of income through which other needs are met.

For occupational therapists to succeed in achieving the outcome of participation of disabled people in work, knowledge of legislative, policy, and economic environments is essential because of the direct impact on effectiveness, relevance and appropriateness of service delivery. The main purpose of this article will be to situate discrimination against disabled people in the world of work as a human rights concern. The focus will be to explore relevant literature, policies and legislation with the aim of showing how these might be relied on to shape services that are designed to promote the participation of people

with disability in work. Recommendations for service models will be made, each based on a case study that was developed using an interpretive biography research design. The argument will be based on people with psychiatric disability<sup>b</sup> because people with psychiatric impairments have been shown to be discriminated against more overtly than other groups particularly with regard to being hired for a job<sup>2,3</sup>. Numerous barriers at human, family, organisational and societal levels have made it difficult for people with mental illness to secure and maintain work in accordance with their own needs<sup>4-7</sup>. It should however be remembered that people with other disabilities confront similar barriers.

## Work as a human rights issue; the consequences of not being able to work

In South Africa, there is a strong correlation between being unemployed and being poor because work is the only viable and sustainable source of income. Almost 50% of the population is considered to be poor or at risk of becoming poor<sup>8</sup>. These realities mean that people who are prevented from participation in work because of barriers confronted as a result of disability, in fact, carry a double burden, namely unemployment and disability.

Human rights approaches recognise power, social justice, anti-discrimination, the indivisibility of rights and the right to health<sup>c</sup>. The tendency to believe that somebody with a psychiatric impairment necessarily will have a reduced capacity to work is largely based on generalisations that are contradicted by many who continue to work. To alter one’s view of a person’s ability to work, solely because of a diagnosis and without verification of reduced work capacity, is discriminatory. Yet, an automatic tendency has been to anticipate incompetence or a reduced ability to maintain work insofar as people with psychiatric disability are concerned. Such practices have led to the exclusion of people with psychiatric impairment from work, turning their impairment into a disability.

Researchers and service providers alike have emphasised the many problems that are experienced as a direct, or indirect, result of stigma. These include reduced self-esteem and a tendency to withdraw<sup>9</sup>, shame and embarrassment<sup>10</sup>, reluctance to seek help<sup>10,11</sup>, reduced compliance with medication<sup>12</sup>, problems with social adaptation<sup>13</sup>, and the knowledge that people in general considered them to be dangerous<sup>11,14</sup>. The prevalence and impact of stigma has been summarised by Johnstone as follows:

“Mental ill-health — and its profound stigmatisation — carries with it a burden of human suffering that at times is not only

<sup>c</sup> London L, Pointer R, Norden P, editors, (undated). Using human rights to promote health equity. Poster pamphlet for School of Public Health and Family Medicine, University of Cape Town and Network for Equity in Health in Southern Africa (Equinet), Zimbabwe.

<sup>a</sup> Also referred to as competitive employment

<sup>b</sup> The Social Model of Disability perspective was taken in the research reported in this article. This evolved from an original definition by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 in which disability is understood as having been imposed, on top of impairments, by a society that isolates and excludes people with impairments from full participation in society (Oliver M. *The Social Model in action: if I had a hammer*, in *Implementing the Social Model of Disability: Theory and Research*, C. Barnes and G. Mercer, editors. 2004, The Disability Press: Leeds). The social model operates from a human rights perspective that insists on the right of disabled people to participate in an integrated society. Its goal is the development of a barrier-free society for all.



incalculable, but incomprehensible to non-afflicted onlookers. Its consequences to both the sufferers of mental ill-health and their families/friends can be deeply dehumanizing, culturally dispossessing and radically alienating. This, in turn, can perpetuate a most cruel injustice, notably, the denial of the mentally ill's moral entitlements to the things that other so-called 'normal' persons may take for granted: function, a sense of place in an intersubjective world, empathic connection with reciprocating others, peace of mind, happiness, participatory citizenship"<sup>6</sup>(p200).

### Work as a basic human need and right

The economic disadvantage of unemployment has a significant impact on health, quality of life and community participation. While alleviation of poverty is an obvious advantage when work is obtained, the concurrent realisation of human potential should not be underestimated. Employment could halt or reverse the disabling process experienced by mental health service users<sup>15</sup>. Research has shown that engagement in work activity can have a therapeutic effect<sup>4, 16, 17</sup> and also "an ameliorating effect on symptoms over time"<sup>18</sup>(p 508). By improving economic independence, practical needs were met through involvement in work<sup>16</sup>. This assumption is embedded not only in the practice of occupational therapy<sup>19-21</sup>, but also that of other rehabilitation professionals<sup>3, 22</sup>. Participation in work allows for social inclusion, and gives people with mental illness opportunities to participate in society as active citizens<sup>15</sup>. Work often plays a role in the way people define themselves and gauge their own value and that of others around them<sup>21</sup>. Again, Boardman et al. agreed with the positive consequences of work:

*"Enabling people to retain or gain employment has a profound effect on more life domains than almost any other medical or social intervention"<sup>15</sup>(p457).*

Linn, Sandifer and Stein demonstrated a definite relationship between health and employment in their prospective study (n=300) undertaken to explore the impact of stress on health<sup>23</sup>. Men who became unemployed during the six-month study (n=30) were compared with an equal number (matched for age and race) who continued to work. Multivariate analysis of variance and covariance revealed significantly greater occurrences of somatisation, depression and anxiety in the unemployed group when compared to the employed group. This group also made significantly more visits to their physicians, used more medication and spent more days sick in bed. A large standard deviation (13.2) for self-esteem in the unemployed group indicated that some men coped better than others with job-loss stress. Those with better self-esteem scores were found to have more support from family and friends. The results strongly suggested that unemployment had an adverse impact on psychological function that, in turn, often manifested in the form of physical symptoms and heightened worry about these.

Marrone concluded a discussion in which he considered the consequences of work and unemployment for people with psychiatric disability with a clear statement that unemployment is much worse for mental health than the stresses of employment<sup>24</sup>.

*"No hard data exist showing that helping people move into employment (even nagging them into it) is bad...Issues that unemployment, particularly long-term unemployment, brings to the fore are depression, feelings of worthlessness, self-pity, self-absorption, higher risk of substance abuse, greater chance of isolation, and poverty"<sup>24</sup>(p187).*

### Disability and unemployment: The size of the problem

The life of every South African is touched in one way or another by the legacy of our past. The impact of historical forces on current employment patterns and prevailing inequality continue to have a major impact on employment of disabled people. Some

explanation for this relative neglect was given in the Commission for Employment Equity Annual Report for 2002-2003<sup>25</sup>; that the priority given to disability equity has been overshadowed by other pressing concerns in our new and fragile democracy. The functioning of crucial social institutions has been stretched by old and new challenges, including ongoing and often increasing inequality, national reconciliation, regional migration, globalisation and the HIV and AIDS pandemic<sup>25</sup>. These challenges are layered upon the sediment of the past dispensation that functions as part of the foundations of the new order with resulting fragmentation<sup>25</sup>.

### Prevalence of disability

The data collected in Census 2001 indicated that 2 255 982 South Africans were living with various forms of disability – the equivalent of 5% of the total population enumerated in this census<sup>26</sup>. The question used to determine the prevalence of disability was framed in such a way as to expand the concept of 'disabled' from a narrow focus on impairment to a broader focus that included human functioning in a social context. The question was: "Does the person have any serious disability that prevents his/her full participation in life activities?" Types of disabilities were classified as 'sight', 'hearing', 'communication', 'physical', 'intellectual' and 'emotional'<sup>26</sup>(p8).

### Disability and unemployment

The Census 2001 Report on Disability Prevalence in South Africa<sup>26</sup> revealed employment figures as shown in Table 1. The definition used for 'employment' in the 2001 Census was a broad one - "those who performed work for pay, profit or family gain in the seven days prior to the survey interview for at least one hour, or who were absent from work during these seven days, but did have some form of work to which to return"<sup>26</sup>(p 31). The term unemployed was used to indicate "those people within the economically active population who: (a) did not work during the seven days prior to the interview, (b) want to work and are available to start work within two weeks of the interview, and (c) have taken active steps to look for work or to start some form of self employment in the four weeks prior to the interview"<sup>26</sup>(p 31). The definitions used in the 2001 Census Report arguably refer to 'participation in work-related activities' rather than 'employment'. This was also the definition used in the study being reported in this article.

Age group (years)	Disabled people	Non-disabled people	Total
15-19	2,5	3,9	3,9
20-24	12,5	22,0	21,7
25-29	21,0	39,6	38,9
30-34	25,2	49,0	47,9
35-39	25,9	52,2	50,8
40-44	25,7	53,5	51,7
45-49	24,8	51,7	49,5
50-54	21,2	46,8	44,3
55-59	16,6	37,9	35,5
60-65	8,7	19,3	18,0
<b>Total</b>	<b>18,6</b>	<b>34,6</b>	<b>33,7</b>

Table 1: Percentage of disabled and non-disabled population employed in 2001 per age group<sup>26</sup>

The employment rate for disabled people was only about 19% compared to 35% of non-disabled persons. The disadvantaged position of disabled people was ascribed to:



- ❖ diverse socioeconomic and social cultural factors, particularly low levels of education, and
- ❖ discrimination in the labour market and negative attitudes of those they live amongst<sup>26</sup>.

About 30% of disabled people had received no education while only 13% of the non-disabled population fell into this category. People with a post-secondary education had the lowest disability prevalence (3%) compared with the levels amongst those who had no schooling (10,5%), those with primary level education (5,2%) and secondary level education (3,9%)<sup>26</sup>.

The South African Labour Market report pegged unemployment of disabled people at 21,3% in 1999 as compared with 16,5% in 1995<sup>27</sup>. The unemployment rate of disabled men rose from 15,2% in 1995 to 21,0% in 1999. These figures looked much better than the alarming statistic reported two years earlier in the White Paper on an Integrated National Disability Strategy that 99% of people with disabilities were not formally employed<sup>28</sup>. However, the employment figure for disabled people in the 2002-2003 Commission for Employment Equity Annual Report confirmed that of the INDS; it was reported to be 1%<sup>25</sup>. Similarly, a report commissioned by the Office on the Status of Disabled Persons found that 2% of employees across all 18 government departments were disabled<sup>29</sup>. Differences in the reported statistics were ascribed to the definitions used for employment and unemployment<sup>d</sup>.

Unemployment statistics for disabled people should be read with consideration to the situation for non-disabled people. High unemployment in South Africa affects countless non-disabled and disabled people alike; many who want and need to work are excluded from employment. Unemployment rose from 17% of the adult population in 1994 to almost 30% by 2001<sup>30</sup>. In 2001, 10.8 million people worked, as compared to 4.5 million who were unemployed and actively seeking work. A further 3.2 million people were estimated as having given up the attempt to find employment despite the fact that they wanted to work<sup>30</sup>. The 2004 Labour Force Survey pegged unemployment at 27,9%<sup>31</sup>; again the official definition was used. The Social Cohesion Report identified one of the most striking features of the South African labour market as being its exceptionally high unemployment rate (pegged at 42% in 2005)<sup>32</sup>. The report states that "with the present focus on redressing the legacies of apartheid, the extent to which unemployment entrenches historic inequalities is troubling"<sup>32</sup> (p 50).

This situation could, to some extent, explain the attitude of indifference that has prevailed concerning disabled people who are unemployed, even when they have an expressed need to work. A high incidence of unemployment would naturally erode the ideal that all who want to benefit from work should necessarily be able to do so. Care should, however, be taken to ensure that barriers imposed by the constraints of the macro South African context, including high unemployment figures, do not mask discrimination against disabled people.

### Legislative and policy environment

The inequality that still characterises South African society brought an impetus for transformation that is focused on the achievement of redress, often through affirmative action. Achievement of equity for South Africans who belong to groups that were designated for redress (black people, disabled people and women) is a strong focus of new labour legislation with a promise to reduce discrimination and open employment opportunities for disabled people. The Employment Equity Act (EEA) of 1998 places emphasis on employment equity, it also legislates affirmative action strategies "to redress the disadvantages in employment experienced in the past, including people

<sup>d</sup> Broad/official definition or narrow definition as defined earlier under the heading 'disability and unemployment'.

with disabilities"<sup>33</sup>(p 23). Medium and large companies are now expected to employ people with disabilities; financial advantages have been put in place to reward employers who comply with recommendations to employ disabled people<sup>33</sup>. Protection is offered to both employees and job-seekers against unfair discrimination based on their disability, particularly with regard to unjust dismissal and hiring. The EEA, together with the Code of Good Practice I and the Technical Assistance Guidelines on the Employment of People with Disabilities<sup>34</sup> provide a strong foundation for the development of affirmative action initiatives and for the implementation of reasonable accommodation. The Basic Conditions of Employment Act of 1997<sup>35</sup> offers protection of disabled people's rights because of improved basic conditions of employment and better protection against discrimination on the grounds of disability. The Skills Development Act of 1998 promulgated tax incentives for employers who employ people with disabilities. Money allocated specifically for skills development, including learnerships, will be available for the training. It should however be noted that the implementation of these legislative pieces has not been done as anticipated. Nine years after the adoption of the EEA the situation is much the same as before its adoption, suggesting that legislation alone is not sufficient to achieve equity. Particular emphasis should be given to affirmative programmes that are developed specifically to facilitate the entry and the maintained participation of people with disability in the world of work.

### International policies underpinning local policies

#### Standard Rules on the Equalisation of Opportunities for Persons with Disabilities<sup>36</sup>

The United Nations Standard Rules for the Equalisation of Opportunities for Disabled Persons ask for a strong moral and political commitment by governments. They guide policy-making and action to ensure that persons with disabilities may exercise the same rights and obligations as other citizens. One of the objectives of the Standard Rules was captured in the INDS as follows: "emphasise that the process through which every aspect of the organisation of society is made accessible to all as a basic objective of socio-economic development"<sup>28</sup>(p 16). The Standard Rules provide clear guidelines, set standards and point out how to prevent discriminatory practices through an integrated approach. The impact of this framework is international uniformity and a standard against which countries can measure their own disability policies.

#### National policies designed to promote equity

##### The White Paper on An Integrated National Disability Strategy (INDS)<sup>28</sup>

The INDS has as its foundation the new South African Constitution that was adopted in 1996 and was informed by the United Nations Standard Rules on the Equalisation of Opportunities<sup>29</sup>. Involvement of people with disabilities in the process of transformation was adopted as the key principle by disabled people's movements. Other essential aspects of the INDS are:

- ❖ Endorsement of the principles of the social model of disability.
- ❖ Acknowledgement of a strong relationship between disability and poverty.
- ❖ Identification of people with severe mental disabilities as one of the traditionally disadvantaged groups in South Africa.
- ❖ Repositioning of disability as a human rights issue. This resulted in an acknowledgement of the premise proposed by the social model for disability, that, if society cannot cater for people with disabilities, it is society that must change<sup>29</sup>.

The ultimate goal of the INDS is for disabled people to play a





full participatory role in society. This is important for people with disabilities because it is a break from traditional views such as the medical model or the welfare model<sup>28</sup>.

### The Disability Rights Charter of South Africa<sup>37</sup>

The Disability Rights Charter of South Africa aims to promote equal opportunities for all disabled people. It asserts the right of all disabled people to live independently in a safe environment, free from all forms of discrimination, exploitation and abuse<sup>29</sup>. This charter, developed by disabled people, for disabled people, demonstrates the political impetus for protection of disabled people's rights.

### Macro economic environment

The availability of work opportunities is linked with broader economic environments; employment of disabled people is therefore dependent on economic growth, the overall rate of employment and times of labour shortage (for example, during times of war)<sup>15</sup>. The growth rate in South Africa has been consistent, but relatively low, during the first decade of democracy. In addition, employment in the formal sector has stagnated, and growth in the informal sector has begun to slow down<sup>30</sup>. Given the current unemployment levels, neither economic growth, nor the overall rate of employment can be relied on to alleviate the problem. Gendered patterns of employment, with men having a significantly better employment rate than women, and marked spatial and geographical disparities due to rapid urbanisation have also been cause for concern<sup>32</sup>. Other features of the South African labour market that were deemed problematic were<sup>32</sup>:

- ❖ Growth in the South African economy has occurred in the informal sector, therefore not offering employment opportunities to the many young job-seekers who wish to enter the labour market.
- ❖ Employment equity has been a major focal point and will continue to be a concern whilst inequalities prevail. Racial and gender inequalities (ie, white and male) persist in the more skilled and managerial occupations; even though Africans, Coloureds and Indians constitute the majority of the total workforce.
- ❖ Skills promotion has been an increasingly important consideration; this is because of a racially skewed skill base and marked shortages in technical and managerial skills in the South African workforce.

### Occupational science and occupational justice

Occupational justice<sup>e</sup> may be understood to be prevailing when the unemployment rate amongst disabled people and non-disabled people is the same. Disabled people in South Africa are, therefore, seen to be experiencing occupational injustice because unemployment is higher than that of the general population. This situation calls for occupational therapists to intervene, using occupational science as a conceptual framework.

*"Occupational science is a basic science devoted to the study of the human as an occupational being. As a basic science it is free to pursue the widest and deepest questions concerning human beings as actors who adapt to the challenges of their environments via the use of skill and capacities organized or categorized as occupation"*<sup>38</sup> (p5).

The discussion thus far would have illustrated the fact that exclusion from work impacts negatively on the health and wellness of disabled people because of the many advantages of work itself. It should also be understood that equal opportunity to participate in work should be seen as a human right. It therefore becomes the responsibility of occupational therapists to find ways in which

<sup>e</sup> Occupational justice occurs when economic, political and social forces create equitable opportunities and the means for people to choose, organise and perform occupations they find useful or meaningful in their environment (Townsend & Wilcock; 2004).

barriers can be overcome and participation achieved. The profession should not be satisfied when rehabilitation is focused only on alleviation of symptoms associated with impairments. Instead, efforts should be directed towards achievement of work outcomes in partnership with disabled people themselves, employers and/or other service providers. Vulnerable groups, such as people with psychiatric disability, might require the facilitation of professionals for their own agency to be developed in such a way as to allow them to claim their right to equality.

A range of service models, each with variations in approach, has been developed as possible strategies through which employment can be supported and maintained. These include transitional employment, supported employment, individual placement and support, natural supports and sheltered workshops<sup>39</sup> as well as reasonable accommodation, consumer-run business, affirmative business, micro-enterprise<sup>40</sup>. The remainder of the article will focus on three strategies that emerged as strong influences in a study that explored the influences that impact on the work-lives of people with psychiatric disability, namely supported employment, reasonable accommodation and temporary employment placement.

### Methodology

An interpretive biography design, situated within a post-modern orientation, was done to explore the influences that impacted on the work-lives of people with psychiatric disability. The aim of the study was to better understand factors that promote or hinder the participation of people with psychiatric disability in work. The discussion in this article will focus on three participants that were extrapolated from the sample of 17. Purposive sampling, in particular maximum variation sampling<sup>41</sup>, was used to select the original sample of 17 participants; however, the subset of participants reported on in this article was chosen because their experiences illustrated the use of service models that will be proposed as effective strategies that can be used to achieve work outcomes.

Data construction involved the use of narrative interviews and observation. On average, three interviews were conducted with each participant spread out to cover at least six months, so as to ensure prolonged engagement and to allow for member checking to be done.

At the start of the first interview participants were invited to relate their story of living with a psychiatric disability and work, or wanting to work. The second interview took place after the first interview had been transcribed; questions that emerged during transcription and initial analysis of the first interview were discussed in the second interview. Participants were also invited to elaborate on their stories, as told in the first interview, relating particular aspects in more depth. Reflections and ideas that came to mind between interviews were also discussed. In the third interview emerging ideas were discussed with participants.

This project was situated within a postmodern perspective, such as the establishment of truth and legitimisation which was done through questioning of verisimilitude which is said to be the ability to reproduce and deconstruct the reproductions and simulations that structure the real. The process allowed participants to revisit the experiences they shared, often adding depth or specificity. It also allowed them to rethink their own constructions in the light of an emerging framework that included the views of other participants.

Data were analysed through analysis of narrative as a 'first level' analysis. This was followed by narrative analysis, the main strategy used to uncover the influences that impacted on participants' work-lives. This analysis was done through the process of constructing biographies; this could also be understood as a 'second level' analysis. The construction of biographies commenced immediately following the first interviews. The biographies were further developed, altered and refined as insights emerged during the first level analysis and after each interview. Biographies captured turning



point events that shaped participants' work narratives.

The study received ethical clearance from the University of Cape Town, Health Science Faculty Ethical Committee. Written informed consent was obtained before data collection started and renegotiated verbally at the start of each interview.

## Supported employment

Supported employment has been defined as "competitive employment in an integrated setting with ongoing support services for individuals with the most severe disabilities"<sup>42</sup>(p548). The purpose of supported employment programmes is "to promote self-sufficiency and a more integrated and improved quality of life by helping persons with disabilities pursue job opportunities in traditional work environments at equal pay to non-disabled persons"<sup>43</sup>(p53). Harold benefited from participation in a supported employment programme.

*Harold had been at university for one month, having won a scholarship to study French literature, when he was first diagnosed with paranoid schizophrenia. He would continue his life with active symptoms associated with paranoid schizophrenia that never completely disappeared. After one more unsuccessful attempt to study, Harold found work in a library and was able to maintain this for one year before a prolonged period of unemployment (13 years). He then joined a supported employment programme and was assisted to find administrative work in a library.*

Within the supported employment programme Harold learnt how to monitor his daily activities, to prevent over-exhaustion which led to intrusive hallucinations and to communicate his needs clearly, as shown in the excerpt from one of the interviews:

*"I did ask, I said I would like to sit down, I would like to be out of the mainstream and please, I don't want to speak on the telephone, or handle money, because I still have a problem counting, I can't count very well. And I... I don't mind talking to people, but I don't... I don't want a desk job." [Harold]*

Harold was able to maintain his contracted work hours (four hours per day for four days a week). He considered work to be a valued opportunity; he enjoyed the contact with his co-workers and loved being surrounded by books. He explained how his current work situation resembled the dreams he initially had for his future after leaving school. Work had had a major positive impact on his identity and gave him new hope for the future:

*"I was so depressed, I couldn't do anything properly, it was, .. it was like I'd become a drop out in society, I disappointed my parents, my family. At school I won 5 prizes in standard 9 and 4 in matric, and when I did go to [Name of University] I got a first in [subject]. So I had small achievements, but like, I can't study. So I'm hoping in this job... they will renew my contract so that I can work for at least 10 years, or so, because (short pause) you know, I'm not completely stupid even though I am disabled, I would like a bit of status in my life, and I really would like to get back my self respect." [Harold]*

Previous research has shown supported employment to be more successful than traditional vocational rehabilitation in the achievement of work outcomes<sup>16, 44, 45</sup>. The supported employment concept, which originated in the United States, is based on the assumption that "when the right type, and intensity, of support is provided, people with the most severe disabilities can (and should be) integrated into the labour market"<sup>46</sup>(p40). Essential steps taken as part of supported employment comprise assessment, job finding, job analysis, matching and job coaching<sup>46</sup>. Supported employment affords employment opportunities for disabled people who fulfil the requirements of the job and are paid accordingly. Employment specialists, often called 'job coaches', provide ongoing support. The nature of support offered is determined by the needs of the worker, or by the particular supported

employment programme. Support could include:

- ❖ transportation
- ❖ training, for example, money handling, grooming, use of transportation, or the management of symptoms
- ❖ programme development, including developing person-centred instructional plans such as behavioural intervention programmes
- ❖ job advocacy such as advocating for a participant at the job site with employers, co-workers and customers
- ❖ non-job advocacy, for example, advocating for a participant, but not related to work, with parents, landlords, case managers, therapists, school personnel, bank personnel, doctors, etc., evaluation such as analysing a person's employment potential by interviewing him or her, reviewing records, communicating with guardians or involved agencies, and observing the individual in real or simulated work settings<sup>43</sup>.

## Transitional Employment (TE)

*Andrew never completed school and was not able to work for more than a week in any of the entry-level jobs he attempted. This all changed when he started to attend Fountain House and was placed in the Transitional Employment (TE) programme. Through his involvement in TE Andrew began to trust his ability to participate in work. He relied heavily on feedback from other members that they thought he would succeed and felt he could ask them to explain things he did not understand. Andrew improved his own performance as a worker whilst in the TE programme and was assisted during negotiation for his permanent job by its staff. Andrew found work as a security man and general assistant at a home for older people. He used a 'Walkman' to block out the voices that he heard whenever he was alone. Andrew also experienced symptoms associated with an obsessive compulsive disorder (OCD). This was a more recent problem that further complicated his life that had been severely affected by schizophrenia (diagnosed when he was still at school). However, accommodation was made at work when symptoms associated with OCD made it difficult for Andrew to perform some of his work tasks, for example, he was no longer expected to assist with washing the residents. This accommodation was crucial; without it Andrew might not have been able to continue working.*

The TE programme referred to in this article was affiliated to Fountain House South Africa, a club for men and women with mental illness that makes use of an adapted form of the New York Clubhouse Model<sup>47</sup>. The programme comprises 12-week transitional placements through which club members rotate in order to gain experience and build confidence. Andrew, one of the participants who had experienced unsuccessful attempts at work without formal support, repeatedly highlighted the value of being in the TE programme:

*"...I went to work every.. day, I got up. I had support, that was the main thing, and we were told if you're not feeling well, you can stay at home. But it was not strict actually it was just we learn to work and it's normal life, just it was a lot of support at Fountain House...*

*On my life.. it's changed my whole life, I wouldn't have been where I am to-day.. Fountain House at least have helped me to get somewhere,.. where I'm satisfied where I am...*

*It's starting all over.. I've been born again, honestly. I thought my life was over. And when I had the hallucinations, they knew I had it at Fountain House .. they just said to me "listen, go for it". I told them I'm scared, whatever, they told me go for it, they told me how to deal with the situation, and my hallucinations stopped at work.. honest, it's good man." [Andrew]*

The knowledge that work was safeguarded in the event of symptoms becoming worse, or even during relapse, was invaluable. This seemed to be a key ingredient in the success of the TE programme. Donovan's life story clearly demonstrated the role



of TE in his process of finding competitive employment.

Donovan described himself as having been the 'golden boy' of the family because he was 'bright' and also an entertainer (a member of a cultural band); this, he explained, made the early stages of illness difficult, like "falling off the pedestal". He had been working for a few weeks when he first experienced bipolar mood disorder. The initial years were very difficult because he was incorrectly diagnosed and treated which resulted in numerous admissions. Donovan had more jobs than he was able to remember, each lasting a few weeks. Donovan then joined Fountain House and shortly after that he entered into the TE programme. During his sixth work placement Donovan decided that he did not want to leave the company and he negotiated a long-term work contract for himself. This contract with the company was subsequently changed into a permanent position.

The TE placements he had successfully completed were varied. Most of these required that Donovan did manual labour; all were jobs that were far removed from the type of future he had anticipated for himself. Even in his current work Donovan had less prominence in the community than his family was used to having, but he compensated for this by becoming involved in public relations programmes at work. Donovan took on an activist role for people with psychiatric disability; his experiences were portrayed in a number of local newspapers and he spoke at workshops and conferences where work and disability were discussed. He continued to attend a support group for those in the TE programme because he believed his own success would motivate others and because of the credibility he had within the group.

Donovan talked about the impact of knowing that his job would be safe in the excerpt below:

"But, just the fact that I knew that if there was something to go wrong, I'm not gonna lose my job and things like that. Whereas before, that's usually what would happen, like I mean I'd crack up and everything and I'd lose a good job and stuff like that. And, there was nothing, there was no support or nothing backing me up and at the end of the day, then I have to start right at the beginning again..." [Donovan]

For Donovan, Fountain House and the TE programme seemed to function as a 'safety net' when he needed it. He explained that he, unlike some of the others in TE placements, never needed Fountain House staff to help him with his work physically. Instead, he seemed to benefit from knowing that they would be available in case he needed their assistance. This kept him going independently, unlike previous attempts, when he worked without a 'safety net'.

The TE programme provided participants with a testing ground. They were able to test their own competence against the demands of a real job in the open labour market. Success within the TEP instilled confidence in their ability to work.

Transitional Employment programmes have been found to be a strong enabling mechanism for people with psychiatric disability to develop a worker identity and maintain work in the open labour market. TE programmes are different from supported employment in a number of ways. Work obtained through a supported employment programme is held by the disabled person and is usually permanent. TE jobs are held by the service providers who identify suitable workers with disability to place in the position for a defined period of time. Recruitment, training and placement of workers will usually be the responsibility of the service provider. People with disabilities who join a TE programme would usually rotate through available placements until they are ready to find employment outside the programme.

### Reasonable accommodation

Harold's story was previously used to show the value of supported employment; it similarly illustrated the power of reasonable accommodation. Another person who benefited from reasonable accommodation was Andrew.

Reasonable accommodation within regular work environments is one of the most obvious strategies that can be used to facilitate continued participation of disabled people in work. However, it has been my experience that successful accommodation requires relatively sophisticated knowledge that will allow:

- ❖ a goodness of fit between the inherent<sup>f</sup> requirements of the job on the one hand, and performance components (with a particular focus on volition), skills and experience on the other,
- ❖ assessments that will reveal barriers to participation and facilitators even if these are not immediately obvious to the person with psychiatric disability him/herself,
- ❖ creation of a sensitive, yet firm, balance between making accommodations and insisting that inherent requirements of the job are competently achieved,
- ❖ creation of a partnership (with disabled person being one partner) that will be relied on to agree on reasonable accommodation required, as well as the implementation and evaluation thereof.

Barriers faced by disabled people include physical obstacles, systemic barriers and attitudinal barriers<sup>33</sup>. Discrimination is a barrier that seems to affect people with psychiatric disability particularly negatively; this is important when considering that attitudinal barriers are the most difficult to overcome.

Legislation, including the Employment Equity Act of 1998 and the Code of Good Practice promote the adoption of a social model of disability that expects rehabilitation professionals to advocate for removal of barriers and employment equity. The accommodation of people with psychiatric disability is usually relatively inexpensive and could be very effective. Examples include:

- ❖ adjustment of work hours and leave, including sick leave.
- ❖ providing specialised supervision, training and support.
- ❖ educating co-workers about disability.

### Conclusions and recommendations

If the power of occupation to fulfil people's needs is accepted, it would follow that the availability of occupation to all who wish to participate in it is an important consideration. Occupational justice "is about recognising and providing for the occupational needs of individuals and communities as part of a fair and empowering society"<sup>48</sup>(p84). When people's occupational engagement is prevented by a set of external limitations on their choices and/or opportunities, occupational injustice will be the result. The stigma associated with psychiatric disability causes the type of exclusion that leads to occupational injustice, particularly in an environment where opportunities for occupational engagement are further limited by resource constraints. Occupational injustice can be counteracted through recognition of the occupational nature and needs of people and through the creation of policies "that allow people's occupational nature and need to flourish"<sup>48</sup>(p84).

A first criticism of vocational rehabilitation programmes in the South African context is that these are usually situated in hospitals or other institutional contexts. Follow through into natural work contexts has not been offered as a part of these programmes. The implication is that people with psychiatric impairment who are suited to work in competitive employment have been left to their own devices post-discharge. A second criticism is that people with disability are expected to fit into a world created to meet the needs, and match the abilities, of non-disabled people. Emphasis should, however, also be placed on changing the environment to remove barriers that prevent equal participation of disabled people. This would be in line with the Social Model of Disability that considers the burden of disability to result from environmental barriers rather than from the impairment or health condition. Such a stance would furthermore be more closely aligned with South African labour legislation and more in keeping with the promotion of occupational justice. Reasonable accommodation should, therefore, be made in order to equalise opportunities for maintained work.

<sup>f</sup> Inherent requirements should be differentiated from general requirements of the job.





## Natural work contexts are important

A key ingredient that led to maintained involvement in work seemed to be a sense of 'belonging' or, in other words, for experiences of otherness to be resolved. Ongoing successful participation in work seemed to be a powerful ingredient that fostered success. The power of this domain was understood to be linked to the resolution of otherness. Maintained participation in valued occupation reduced experiences of otherness and vice versa. It also indirectly assisted with the preservation of authentic identity. When work was continued, despite moderate symptoms, the alienating consequence of inauthentic identity was reduced. This improved the flexibility with which identity shifts could be accommodated without secondary damage being experienced. Without the natural context, experiences of otherness cannot be resolved and the disabled person might not develop a reliable worker identity. A reliable worker identity appeared to develop when a real contribution was made in the workplace whilst being accepted by co-workers who knew about the worker's psychiatric impairment. The acceptance of others, who knew about the psychiatric impairment, had a remarkably positive impact on resolving experiences of otherness.

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