Getting Your Life Back

By Diane Froggatt

Until recently, it was not part of medical treatment to do more than relieve the positive symptoms of mental illness with the anti-psychotic medications available. The job was done when the medications relieved these symptoms. However, for some years now, partly as a result of the consumer and family movements for mental illness, and partly due to an improved understanding of the working and efficacy of medications, a new paradigm has arisen for these conditions and in particular for schizophrenia.

Many consumers, mostly those who have seen improvement in their condition, have come forward to say that there is more to their lives than disease and symptoms of disease and they want their carers to have a holistic approach to treating them. They have stressed that even with some symptoms they can function if given the opportunity to develop or regain skills, to develop support networks and regain the self-respect that many of them have lost owing to periods of ill health.

In addition to medication and support people need something that will uplift the spirit and the mind. This is what people may have in mind when they speak of "recovery": a revitalization of the spirit, a renewal of the identity of the person. For some this idea may seem cruel, for despite all their struggling, even to get through one day takes all their energy. For others, societal and cultural beliefs may work against them even when they try to move towards a better life.

Rehabilitating people from psychiatric illness can be highly labour intensive. In some mental health services it requires one-on-one support from a mental health worker to motivate the person and direct the process. Even in the developed world such services are not widespread. In other services the emphasis is on groups of people working together to achieve a common purpose. Large populations and economic deprivation make it difficult for such help to occur in developing countries. Nevertheless efforts are being made and we highlight some types of initiatives below.

Comprehensive Care

According to Kim Mueser et al., illness management programs have traditionally provided information and taught strategies for adhering to treatment recommendations and minimizing symptoms and relapses. However, many programs go beyond this focus on psychopathology and strive to improve self-efficacy and self-esteem and to foster skills that help people pursue their personal goals. Enhanced coping and the ability to formulate and achieve goals are critical aspects of rehabilitation and are in line with the recent emphasis on recovery in the mental health self help movement.. . . Common themes of recovery are the development of self-confidence, of a self-concept beyond the illness, of enjoyment of the world, and of a sense of well-being, hope, and optimism."

The challenges are great. Not least of these is the limited efficacy of medications which may leave people with many of the symptoms that prevent them from living a normal life: anxieties dealing with people; poverty of expression; misinterpretation of the motives of others; inability to experience pleasure; difficulty coping with authority; extreme excitement or slowness of action. The second generation medications have given hope to many, but are still a long way from returning everyone to a reasonable life. Nevertheless, t is generally accepted that for people who have had more than two or three acute psychotic episodes no improvement in their condition will occur without the help of regular medications in appropriate doses.

Clinical programs that go beyond medication management, adding other aspects of care like psychoeducation, family psychoeducation, behavioural tailoring; skills training, etc., increase the opportunity for people to function better and to overcome aspects of illness such as poor memory, difficulty initiating activity; and social deficits. Recent studies have shown that "cognitive behavioural treatment is more effective than supportive counseling or standard care in reducing the severity of psychotic

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symptoms. Furthermore, studies that assess negative symptoms, such as social withdrawal and anhedonia (inability to experience pleasure), also report beneficial effects from cognitive-behavioural therapy on these symptoms."(Ibid.).

Family interventions using family and friends as a resource to help improve outcome for the patient, makes good sense for the doctor or team as well as for the family and consumer. (Members will be familiar with our program to promote family participation: "Families as partners in Care", and our booklet "Principles for Family Work"). Recruiting families for such programs is a necessary component for family work, because families do not always recognize the need for them to be involved in the care of their relative who is unwell.

Peer-to-Peer Initiatives

In the last issue of the WFSAD Newsletter (2005-3) we published excerpts from a booklet "Let us Try and See" developed by the Schizophrenia Awareness Association (SAA) located in Pune, India. The SAA is a peer-to-peer based organization which also welcomes relatives of its members. Their program gives direction to members about improving their quality of life.

Similar programs that go beyond support have sprung up in many places where people with experience of mental illness get together to develop meaningful work or recreational activities to help them in their journey towards a better life.

Clubhouse

One of the first peer to peer initiatives was the development of Fountain House, New York, from which have sprung more than 400 clubhouses in 32 countries. Fountain House is dedicated to "the recovery of men and women with mental illness by providing opportunities for our members to live, work and learn while contributing their talents through a community of mutual support." It now employs staff in addition to members to run its substantial business. (www.fountainhouse.org) The clubhouse idea has been adopted in many places outside the exact Fountain House model, because each place, each culture, each economy and government system is different. Some clubhouses, for example, provide or manage housing initiatives. In all these clubhouses there is a spirit of cordiality and each provides education, recreation and work activities for its members.

Consumer Run Businesses

Different from clubhouses, these initiatives are more prevalent in countries where government disability payments are the norm for people with psychiatric illnesses. They provide work for consumers, often on an hourly or daily basis, recognizing the need for people to have the self-respect that comes from work along with the limitations that the illness can put on the amount of time you can work. They are usually developed in conjunction with grants from government sources with assistance from charitable foundations.

Social Firms

Initiatives similar to consumer-run businesses are prevalent in Europe where they are described as **social firms**. Their purpose is to provide employment at market wages for people with psychiatric disability. If employees require accommodations or modifications to enable them to do the job these are available. A quarter of the employees of these firms are those with psychiatric disabilities or other difficulties. Social firms usually have a two-pronged direction. They must fulfil the social aspect of the enterprise as well as the trading and economic aspect. Thus the business must be viable in order to succeed. More than 50% of income must be derived from sales, according to Social Firms UK (www.socialfirms.co.uk). In the market place they must compete with non-social businesses. Social firms are usually led by people with business entrepreneurship along with social sector know-how.

Areas in which these firms have been successful are services in gardening; horticulture; cleaning; printing/print finishing; graphic design, catering and restaurant owndership. It must be emphasized that developing these enterprises takes considerable time (3-5 years) and considerable skill.

Vocational Training/ Supported Employment

"A majority of severely mentally ill people would like to work and there are compelling ethical, social and clinical reasons for helping them achieve this goal. Pre-vocational Training and Supported Employment are two different

approaches to helping severely mentally ill people obtain employment. The key principle of Pre-vocational Training is that a period of preparation is necessary before entering competitive employment. In contrast, a key principle of Supported Employment is that placement in competitive employment should occur as quickly as possible, followed by support and training on the job. Supported employment is more effective than Pre-vocational Training in helping severely mentally ill people to obtain competitive employment."[i]

This view has been current for some time. One of the reasons that supportive employment is favoured is that transferring skills taught in one location and applying these same skills to a job in another location does not seem to work very well, particularly for people with schizophrenia. With supported employment, consumers receive training at the location where they will be working.

The goal of supported employment is to help those with severe mental illness (who have shown an interest in working) find and keep competitive jobs. Supported employment usually involves a person who acts as an intermediary between the person starting the job and the new workplace.

Research suggests that the new employee needs this person to smooth out social issues with co-workers rather than to give further instruction in the job process. In the last issue of the WFSAD Newsletter (2005-3, p.8) we briefly described a "Toolkit for Supported Employment" offered on the web by the US government's Mental Health Services Administration (SAMSHA) Center for Mental Health Services. The booklet was designed to introduce strategies needed to be an effective "employment specialist" – a job that is directly linked to the treatment team. Specialists help people look for work and continue to support the consumer as long as they want assistance.

Another manual in the same vein is *A Working Life for People with Severe Mental illness* by Deborah R. Becker and Robert E. Drake, reviewed in the WFSAD Newsletter 2004-1, p.14.

Work Opportunities Provided by Voluntary Organizations

In this issue Ratna Chibber gives a short report on the opening of a second shop at AASHA (support organization in Chennai, India). The second shop, like the first, will employ people with psychiatric disorders whose training will be conducted "on the job" by AASHA members. For the longer article on the first shop see WFSAD Newsletter 2003-4, p11. In the case of AASHA, the family organization developed the means of employing its consumers and then employed them.

It is not always possible to offer work paid at market rates, but an equally important factor is giving people meaningful things to do in a friendly atmosphere. At Turning Point, a Calcutta mental health agency, the goal is to build self-esteem through daily activities making handicrafts, painting and doing other work around the agency. One parent said of her daughter: "Slowly we noticed a challenging and winning attitude in her. She started doing more and more work. In the cultural programme, she was motivated to perform on stage."

Talent Development

Learning a language takes on greater meaning and interest when it is done through a secondary medium e.g. taking a photography course in the language you are learning. In the same way rehabilitation can be better achieved while doing something that has a purpose beyond the notion of rehabilitation. Using this technique, many recreational or learning activities have been developed.

Such an initiative is the development of the dance troupe of people (who had experienced mental illness) in Istanbul, Turkey. They were so successful that they have toured in several countries. The group was initiated by the Schizophrenia Society in Istanbul. Similarly, various acting, theatre and even film groups have sprung up giving opportunities to consumers to prepare scripts, build scenery, act, produce and more.

Rehabilitation is a vast field of endeavour in which we can all take part, whether it is befriending a person who has a mental illness, or providing a service. This article has only scratched the surface. We look forward to receiving news of your successful ventures.