SOCIAL REHABILITATION: WHAT ARE THE ISSUES?

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DVA National Rehabilitation Conference 2004

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Psychosocial rehabilitation, mental illness and disability: defining our language

Psychosocial rehabilitation is the universally accepted term which refers to social rehabilitation, involving cognitive and functional gains as well as the development of social skills that can be achieved for clients undertaking rehabilitation.

Indeed, before examining psychosocial rehabilitation it is important to be aware of the context in which this term is used. Understanding of mental illness in the community – or 'mental health literacy' as it is sometimes called – is generally very poor. This leads to untreated symptoms, stigma and often great distress to those affected and their families. The vocabulary associated with mental illness can also be misleading if misused, as is often the case. 'Mental illness', 'psychiatric disability', 'psychiatric disorder', 'high-prevalence disorders', 'low-prevalence disorders', 'mental health problems' and 'mental health issues' are all used, sometimes interchangeably.

When most people hear the word 'disability' they almost always think of a physical disability. It is important for those affected by a mental illness to recognise that disability can be a consequence of any illness – a consequence that prevents someone from engaging with the world around them in a way taken for granted by the rest of the population. Many people experience some of the symptoms of a mental illness but are still able to work or enjoy an active life in the community. There are others however who are more severely affected by the illness, resulting in reduced quality of life and community participation. It is the disabling effects of a mental illness or psychiatric disorder that is the focus of psychosocial rehabilitation.

Symptoms such as panic attacks, mood swings, and episodes of psychosis, depression and anxiety are not just traumatic in themselves but may result in the person struggling to maintain the basic skills required for daily living. The skills and confidence required for everyday communication, making decisions, planning, processing information, concentration, seeing a task through, maintaining

relationships and self-care routines can all be eroded by both the illness and, importantly, the person's response to it. Combined with this can be the numbing or 'fogging' side-effects of medication used to treat the symptoms, affecting the person's ability to tune in to their environment and interact accordingly. For many this can result in a disengagement from usual activities, social contact and situations that seem to make too many demands.

The disability is compounded by the accompanying social withdrawal. It is generally more difficult to admit to psychological frailty than to a physical injury or poor physical health. Our sense of identity – who we are in our community, our status amongst our peers and self-respect – is linked far more to our mental health status than our physical health status. So long as we can tell a joke or story to our mates or talk to the neighbours about the footy, we are part of our community.

It is therefore very important to educate the community about mental illness and to work with individuals to help them recognise that mental illness is not something to deny or retreat from, but is a common condition that can be treated and managed. The coordination of clinical treatment and psychosocial support services is crucial to achieving this outcome.

What do we mean by psychosocial rehabilitation?

Psychosocial rehabilitation has received increasing attention over the past ten years, during the period that 'care in the community' has become the norm for people affected by mental illness (Anthony, 1996; Barton, 1999). An important potential benefit of psychosocial rehabilitation suggested by these studies is a reduction in the frequency and severity of symptoms and improved quality-of-life.

The most accepted definition of psychosocial rehabilitation is from Cnaan et al:

> The process of facilitating an individual's restoration to an optimal level of independent functioning in the community . . . psychosocial rehabilitation encourages people to participate actively with others in the attainment of mental health and social competence goals. [Cnaan et al, 1998]

This process has been codified by Cnaan and others (1990) in a set of principles recognised by the International Association for Psychological Rehabilitation Services (IAPRS). These include:

IAPRS Principles of Psychosocial Rehabilitation

- Recognition of under-utilisation of human capacity.
- Equipping people with skills.
- People have a right to and responsibility for self-determination.
- Services should be provided in as normalised environment as possible.
- Differential needs and care.
- Commitment from staff members.
- Care is provided in an intimate environment without authoritative shields and barriers.
- Early intervention.

- Environmental change.
- Work-centred process.
- Emphasis on social rather than medical model of care.
- Emphasis on the here-and-now rather than problems from the past.

This rehabilitation process has three stages: assessment, planning and intervention – with a focus on the particular individual's needs at each part of the process (Anthony & Liberman, 1986).

Why is psychosocial rehabilitation so important?

Being able to take some control over one's symptoms and having the confidence to set goals, plan ahead and develop skills is a key factor in the process of rehabilitation and, for many, the start of the process of recovery. It is important that this taking control can extend to the rest of the person's life, and central to this is having somewhere to go to in the wider community that supports people to make these steps in a safe non-judgmental setting. This is very much the role of psychosocial rehabilitation services.

Many people who have experienced a mental illness will talk of the loneliness, isolation, loss of meaningful relationships and disconnection from the community they feel.

Recovery cannot take place in a vacuum. In addition to clinical treatment, it is crucial that there is also somewhere to go in the day, to feel welcome and included, to be part of a community, to learn new skills, to assist and share experiences with others and contribute and to feel valued. There is no motivation to learn new skills, whether they be cooking or computers, if someone's days are empty and friendless. Alcohol and daytime TV can easily be used as a form of anaesthetic to numb the depressing reality of the situation. We all need to feel part of a group, but if someone's sole social activity is a weekly barbeque, this is not helping the person to lead a more fulfilling life in the wider community.

An obvious but sometimes forgotten benefit of having somewhere to go in the day is that it quite simply fills up the time. To have endless empty days stretching ahead can be very stressful. One's thoughts and sense of identity inevitably revolve around the past and it becomes increasingly difficult to have either the motivation and confidence to think of the future, or plan ahead for it.

What do psychosocial rehabilitation services provide?

Psychosocial rehabilitation services provide a structured environment with activities ranging from recreation and 'drop-in' to specific skills development.

There are a range of Day Programs (including Clubhouse, skill-based and Drop-In Programs) available to people with a mental illness in Australia, although coverage is very uneven. There are also Outreach and Respite Services in some areas that assist people to develop skills and community connections.

These programs offer opportunities to learn practical skills such as cooking, budgeting, creative pursuits such as art and creative writing, as well as specific skills such as woodwork and using computers. The approaches vary from being run as a course in a series of sessions, to the Clubhouse approach that maintains new skills are more likely to be developed by participants (referred to as members) working alongside staff in the running of the program, with their existing strengths, knowledge and expertise being drawn on wherever possible.

Recreational activities such as bus trips, bowling, sporting activities as well as accessing local community facilities are also a feature of these programs. Some run gender-specific groups with a mix of recreational, educational and social group activities. Specific focus group sessions are run in many rehabilitation programs. These typically aim to develop self esteem, communication skills, relaxation techniques, relationship management, anger management and goal setting. Pre-vocational skills development is an increasing element of rehabilitation. Although there is still some confusion in Australia between the role of the federally funded employment support services and state funded rehabilitation services there are more partnerships developing between these services.

There is an increasing emphasis on health promotion and education, with groups discussing and learning about issues to do with the illness, medication, diet and so on – in recognition of the poor physical health of many people affected by mental illness. Services working in the area of alcohol and substance abuse, gambling and related issues are now more widely promoted but are still limited in availability. The SANE Quit Smoking Program (2004) also specifically addresses the special challenges faced by people with a mental illness who wish to stop smoking.

Drop-In is recognised as an important part of the rehabilitation process. Some people just need somewhere to go and be around other people and do not want to be part of the more structured activities. For some this is the first step and they gradually become more involved with the specific programs on offer, for others Drop-In may be as far as they get, but still provides a sense of connection with the community.

A major reason for attending rehabilitation programs for people with a psychiatric disability is the support gained from one's peers and a sense of 'having permission' to have a mental illness. It is important however that these services are viewed as 'a station on the way' and not the 'end of the line'. A risk that these programs run is that by providing a safe, welcoming environment they become do not encourage people move beyond their 'comfort zone' to access other, mainstream services and to integrate with the broader community. It is important then that rehabilitation services respect the importance of peer support whilst also encouraging wider social involvement. This allows more movement through the programs as there are many who are not able to access services because of limited places.

Barriers to psychosocial rehabilitation

Acceptance that there is a mental illness or recognition of a need generally has to happen before rehabilitation services can work with someone. Some people are so locked up in denial or anger as a result of the illness that this then inhibits them from accessing those rehabilitation services available.

Not having access to information about the illness will prevent some people from recognising the need for rehabilitation. Learning about it helps to put a handle on the experiences, gives it a label and increases the awareness that the illness is experienced by others as well. Education about the illness is now known to be an important contributor to better outcomes in the management of anxiety and depression, but is not necessarily made available by the treatment team.

For some the idea of rehabilitation and recovery can be alarming. There may actually be some anxiety associated with 'getting better'. It may mean starting to take more responsibility and meeting new expectations. This could lead to other people making more demands and possibly showing less patience and understanding. One also has to deal with one's own frustrations with the sometimes slow and fluctuating rate of progress.

Being sick can make people reluctant to plan ahead. Thinking about the future can mean having to confront the present situation, rather than having one's identity being locked up in the past or in the illness.

There is no doubt that mental illness remains misunderstood by the community and misrepresented by the media. As a result many people prefer not to disclose their illness to those around them. Rather than having to explain or request support it is easier to withdraw or seek out the only company they feel safe in.

People may accept that they have a mental health problem but still be reluctant to consider this is something which has a disabling effect on their lives or needs treatment and support.

Many choose not to access programs designed for people with a mental illness as they do not want to associate with the more disabled population who attend them. The media's misleading, unbalanced and sensationalising coverage of mental illness make it understandably difficult for people to associate their personal experience with some of the extreme portrayals they see in newspapers, magazines and on television.

It is also important that clinicians are working towards positive goals with the individual and that the psychiatrist in particular is giving encouraging messages that foster hope, not reinforcing the negative, passive 'illness status' of the person they are treating.

Davidson (2004) asked a sample of people with a mental illness to list the various factors that inhibit rehabilitation and they came up with the following list:

- Being the object of stigma and discrimination
- Experiencing repeated failures and losses

- Losing control of my life, having others make important decisions about my life for me
- The constriction of possibilities, expectations, and roles open to me
- Being confined to a passive, patient role in which I have nothing to offer others
- Negative and paternalistic attitudes, accentuating my deficits and problems
- The lingering presence of institutional culture in community settings.

What are the benefits of psychosocial rehabilitation?

Apart from potential symptom-related outcomes, people who attend rehabilitation programs report that a principal benefit is the opportunity to meet others and do things socially, overcoming the painful isolation and loneliness experienced.

Potential benefits of psychosocial rehabilitation include:

- Skills development – such as budgeting, self-care, communication and vocational skills
- Improved general health – including better diet, reduced substance abuse and general fitness
- Improved confidence – boosting of self-esteem and social competence through development of new skills or re-learning old skills
- Social networks - development of new friendships for ongoing social support
- Increased opportunities to return to work or study.

There are also potential cost efficiencies to government. A study undertaken by the University of South Australia and SANE Australia (Ireland & Morgan, 1996) found that regularly accessing a psychosocial rehabilitation program was associated with reduced demand for clinical services, thus reducing the total health service costs.

Families also benefit from sharing the caring. Attendance at a rehabilitation program often allows relatives and friends a break from their supporting role, giving them time to pursue their own interests (Greenberg, Greenley & Brown, 1997). By supporting and sustaining the caring relationship, rehabilitation programs benefit family and other carers as well as the person with the illness.

Another important benefit is improved understanding of mental illness by the general community. The more people meet and mix with others who have a mental illness, the quicker they will realise the absurdity of the false stereotypes promoted by the media, hopefully contributing to a more tolerant and inclusive society. Psychosocial rehabilitation programs which link with existing services such as Neighbourhood Houses and Leisure Centres and support people to access mainstream clubs and groups, are not only assisting people to connect with their local community but are also helping to educate its members. Personal contact is likely to facilitate positive and less stigmatising attitudes. It is through getting to know someone with a shared

interest, who also happens to have a mental illness, that misconceptions are broken down.

Although not evenly spread throughout Australia, many psychosocial rehabilitation services are able to provide a range of services that encourage participation and personal development for the individuals attending. It is the supportive environment that combines peer support, skills development and structure that fosters an atmosphere of recovery.

Embracing Recovery

Recovery, in the context of mental health, is a term developed at the Boston University Centre for Psychosocial Rehabilitation. As Deegan (1988), Lamb (1994) and others emphasise, recovery does not mean being symptom-free or cured, but refers to a process of accepting, adapting and moving on to make a new life for oneself.

It is important to make the distinction between rehabilitation and recovery.

Rehabilitation refers to the services and technologies that are made available to disabled persons so that they might learn to adapt to their world. Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of disability (Deegan 1988).

> Recovery involves a process of restoring or developing a meaningful sense of belonging and positive sense of identity apart from one's disability and then rebuilding a life in the broader community despite or within the limitations imposed by that disability. (Davidson, 2003).

Rehabilitation services must provide the right environment for recovery to occur. A key component is the importance of being able to take control of one's life, to have a positive sense of personal identity whilst accepting the illness will not be cured but can be managed. It is in this context that the term 'moving on' could be misleading. It may not be possible to leave the illness or trauma totally behind, but it may well be possible to 'move with' some of the symptoms or disabling features and 'rebuild a life in the broader community'. If someone believes they have to be symptom-free to experience a sense of recovery they may be setting themselves an unrealistic goal – but to accept that some of the symptoms can co-exist with recovery promotes an attitude of not so much 'moving on' but 'moving with'.

The more that rehabilitation services provide a supportive environment that promotes the following features, the more likely it is that a sense of self worth and recovery will develop.

Positive factors in recovery (Davidson, 2004)

- A sense of belonging and acceptance from caring others
- Renewed hope and commitment
- Involvement in meaningful activities in the community

- Redefining the illness as only one aspect of a multidimensional sense of self (rather than having my self and life defined by the illness)
- Finding ways to manage the symptoms and impairments associated with the illness
- Experiencing successes and pleasure
- Giving back to, and regaining citizenship in, the broader community.

The challenge for rehabilitation services at the moment however is the last comment listed above, 'regaining citizenship in the broader community'. How do services avoid the risk of becoming a 'disability ghetto' and extend their specialist support into the wider community?

Not only do the individuals with a mental illness need to make adjustments to live a more meaningful life, so some of the services need to build 'ramps' between their programs and local community resources. Once someone has come to terms with their mental illness and is at a point where they can engage in the community, it is important that mainstream community groups are accessible to them. Education of these services to the needs of people with a mental illness is an important component in the grafting of specialist support into mainstream services.

Not everyone travels smoothly in one direction during the process of recovery, and support and treatment will need to be sensitive to varying demands over time. Withdrawal from or a change in medication, an increase in stressors, or just the course of the illness, will mean that many find they have relapsed and are struggling with the symptoms of the illness again. The severity of the relapse, the person's ability to cope with it, the support of friends and family and the support services available will all influence the outcome. For many each relapse is less traumatic as they learn how to recognise the early warning signs and take prompt action, whether this be taking a short break, increased visits to the doctor, peer support or rehabilitation program.

Psychosocial rehabilitation services can play a key role in the process of recovery but should be part of a longer journey that moves people from disability to meaningful participation and inclusion in society.

A comprehensive system of counselling, education, peer support, clinical treatment, therapeutic interventions, information and support to carers, and rehabilitation programs all play a significant part in the individual's recovery to a level of optimal functioning in the community. There needs to be a responsive system of treatment and support, acknowledging that the illness is one part of the person's life not the only focus of it.

What are some of the issues for the Veteran community?

The most common psychiatric conditions in the veteran community are post traumatic stress disorder (PTSD), depression, anxiety disorders and alcohol dependence and abuse.

Although veterans living with a mental illness will share similar symptoms with others in the population with the same diagnosis, they share only with each other the unique characteristics of being a veteran. While they may have served in any conflict from the Second World War through to the more recent Gulf Wars, veterans share a common experience as former serving members of the Defence Force.

They are a population who has chosen a career environment that depends on a highly structured, organised force to be as efficient as possible in the stressful and unpredictable conditions of a war zone. High levels of psychological and physical strength, endurance, cooperation and loyalty are necessary for each individual to carry out their role in such extreme situations.

The responsibility each individual has towards the welfare and survival of others is a demand not paralleled in any other work environment. The recognised qualities of mateship, loyalty, humour and courage become critical. Combined with the shared experience of suffering, trauma, fear, and memory of the sacrifices made by individuals in such extreme times, it is no wonder the loyal bond between veterans remains for life.

The transition from this environment to the less structured one of contemporary civil society in Australia is not always easy and is often not a deliberate choice. Family roles and relationships have become much more fluid over the last few decades, the church and other community institutions are less prominent, with less clarity about the status attached to positions in the community. More people are working than ever before and fewer people are involving themselves in volunteer and community work - making it harder for those not in work to feel a sense of connection with the wider community. An increasing indicator of status is to be frantically busy, constantly in demand and working longer hours, with mobile phones and emails demanding instant attention and leisure time packed with intense social and sporting activities. The common assumption is that the busier and fitter you are, the more value you have.

For veterans returning to a life that may no longer include sharing a home with their families, in a community that has less clearly identified roles and pathways to being involved, it can be a very disorientating experience. It is understandable that the people they have been so closely attached to in active service will be the ones sought out, undoubtedly experiencing similar barriers to integration. Returning home with no clear role or sense of identity other than being a veteran, may be an unanticipated stressor. To go from always operating as part of a unit where each person is clear about who does what where, who follows orders, who makes the decisions, to the unstructured environment of modern living is not an easy transition.

To be part of a group that has not always been embraced by the wider community on return to civilian life – and a wider community that has not been involved in or committed to the war effort in any way – can further disconnect veterans. In contrast to the media’s primary focus on the drama of war, there is less awareness of veterans’ status and needs on their return home.

Anxiety about securing or losing a pension can result in apprehension about terms such as rehabilitation and recovery, creating a state of insecurity rather than the confidence required to rebuild one’s life. For many in the veteran community,

recovery would be associated with improved physical health, a sense of having energy again and no longer feeling physically exhausted. For a population whose lives have depended on a high level of fitness, maintaining a good physical condition would be essential to improved mental health.

Looking ahead: where to from here?

This paper has examined the role psychosocial rehabilitation services can play in recovery, their context and the importance of these services being part of a continuum of support.

It has raised a number of key issues to generate thought, discussion and resolutions, and which we need to talk through, including:

- What are some examples of best practice in Australian or overseas?
- How can community services respect and balance the need for peer group support while encouraging veterans to link in with other networks and groups to ensure the services do not become a 'disability ghetto'?
- Given the fact that nationally, community-based rehabilitation programs are insufficient in number and underfunded for the populations they currently serve, will this result in equity and access issues in the future?

Delegates at the Conference are encouraged to reflect on the many issues raised by the paper and examine, challenge and discuss matters further.

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September 2004

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