



## Parliamentary Inquiry

Darwin, 17<sup>th</sup> October 2011

I would like to thank you for the opportunity to speak here today and want to acknowledge some of the excellent contributions of organisations and individuals to the Inquiry and the research that has been conducted in this field. Many positive changes have already taken place in the time I have worked in mental health in Australia.

Most of points I will raise today I have found supported by research. I would like to add from my experiences as a social worker. Since 2000 I have worked extensively with both carers and consumers in various positions. My positions included managing a Clubhouse, which is both a managements and a hands-on job; off-the street general support, emergency relief and referrals; implementing the MHRP in a CRCC and project management under NRDF, <sup>Partnership 4 organisations</sup> which includes work with individual carers, training of carers and consumers, facilitating networks, outreach and public awareness activities and mental health education and suicide prevention training. Last but not least I also have some personal experience as a mental health carer.

The issues I will present today are those, which have been the most prominent in my practice.

- 1. Stigma and Self-confidence**
- 2. Issues of bureaucratic hurdles**
- 3. Integrated services**
- 4. Challenges of staying in the job**
- 5. Role of families and social support**
- 6. Campaigns for change**

I do regret that I don't feel competent to speak on issues of indigenous, rural and remote issues in mental health and workforce participation.

## 1. Stigma

*"What is worse than hearing voices in your head? --Hearing voices behind your back."*

This was the motto of the 2011 for Schizophrenia Awareness Week by the Schizophrenia Fellowship NSW.

In my experience stigma is probably one of the greatest obstacles and it has many faces and ways of effecting people's lives. This includes what the person with a mental illness believes about him/herself. The reason why people with a mental illness often experience a shattered self-confidence is partly because the illness can be so frightening and unsettling. One woman told me that when your mind is out of control, it's the scariest place to be.

Another reason though why self-confidence has to be built up again, is the stigma of mental illness. This includes the low expectations of people's performance after an episode of mental illness. A consumer who wrote for the magazine of SANE Australia described that 20% of the disruption of all aspects of his life was due to his illness. 80% were due to economical and social repercussions and stigma.

I am shocked time and again when consumers tell me that their doctors told them that they will 'have this for the rest of their life', that 'they will never be able to work again' and 'that they have to stay on medication for the rest of their life'.

No one of us can predict the course of a mental illness. Janet Maher, a brilliant consumer speaker and CEO of PRA in Sydney said that our task as professionals is to hold up the torch of hope. We fail as professionals if we don't promote recovery and give hope when we talk about mental illness. The lack of a vision of recovery has a detrimental effect on a person's perception, especially a young person.

Stigma has many ways of expressing itself. In the workforce we often see that people do not disclose their illness to potential employers, **stats**. Even an

employment consultant said that she thinks that probably only one in five people disclose to them that they have a mental illness.

One mother told me *"My son is really worried that other colleagues find out about his illness, you know, it's man's world. Some smart-ass comments really affect him."*

And a woman with anxiety disorder and depression says:

*"Coming back to work is huge. You have to reassess your whole life, so you also reassess where you fit in at work. Your whole identity is in question. When you apply, you don't want anybody to know that you have this problem. It influences your behaviour if you have to keep a massive part of your life a secret. Also when you work, you have regular doctors appointments, but you don't want anybody to know. There is constant pressure to keep things a secret."*

Disclosure is risky and although many people feel relieved when they have openly spoken about it, it has to remain an individual choice. In a study from 2006, 57% of survey participants had disclosed their mental illness to the employer and 67% of those stated that this had been helpful. But people often have good reasons not to disclose after many experiences such as the following:

*"When I apply for jobs I often get invited for an interview. And all goes well and then when they ask me what I have done in the last few years and I say I have been looking after my mother and I have a mental illness, they start to look at each other and act in a funny way and then they say, ok, we give you a call. Of course I never hear from them again."*

## **2. Issues of bureaucratic hurdles**

Closely related to stigma in terms of causing anxiety and additional stress are issues related to navigating the system of Centrelink, job service providers and other agencies.

We know that most people with a mental illness want to return to the workforce. A study in 2006 showed that 81% of people in a survey were either employed or wanted employment. Yet, the rates of people being in the workforce are low,

lower than in many OECD countries -only 29% in 2003, in comparison to 49% in physical disabilities and 74% in the general community. Not surprising they are lowest for people with psychotic disorders. Only 2 in 10 people with psychotic disorders are employed.

Rather than encouraging workforce participation many policies and regulations are experienced as threat. I have spoken to a number of people who do not consider entering the workforce in fear of losing the security of the DSP. The illness is unpredictable enough. Many people reach a level of relative security after often prolonged periods of instability. Giving up financial security for an endeavour into employment with uncertain outcome is for many too risky.

For some people work capacity assessments become a dooming evil. I remember vividly one man who used to be an employee of Centrelink himself, before he had to give up work because of a crippling depression and anxiety. Every time he received a letter from Centrelink his anxiety increased to a level of nausea and feeling physically paralysed.

I don't want to comment on Job Capacity Assessments but would like to share a couple of quotes from someone working as job service consultants:

*"Some people come in when they are not well, they are being sent by Centrelink. Sometimes jobseekers are assessed by Centrelink to be employed full time. But they are nowhere near being ready for employment. Not even for part time work.*

*One guy came in and for weeks he couldn't ever remember his password to log onto the computer, although it was just his surname. But he was assessed as capable of working full time. One woman came and said to my colleague, "I have a schizophrenia, I am a drug addict and I am homeless. Would you employ me?" My colleague shook her head and the job seeker said, "Why do I have to go through all this rigmoral with finding a job then?"*

Recovery has no time frame, is not predictable and depends on many personal, social, environmental and medical factors. The Personal Support Program was a useful program, which understood that many people need assistance addressing the myriad of obstacles. The assistance is not only needed because the effect of

the illness and issues like addiction, homelessness etc. Everyone who works in the field or is personally dependent on services knows that the diversification of services is often results in an incomprehensible maze. The time frame of two years was often sufficient, but sometimes it was not.

At the same time it is important that we see the diversity and wide ranging skill levels of people with mental illness. Having a mental illness usually does not affect the person's intellectual abilities. Our CEO's testimony is a great example.

The Personal Helpers and Mentors Program has gone some necessary steps further by allowing the *consumer* to determine what the outcome of the intervention should be. It has no time frame and does not require a clinical diagnosis. Many people agree that –if delivered well- it is probably the best program which has been implemented in many years. Unfortunately some PHaMs providers struggle to have a well-educated workforce.

I believe that PHaMs programs could possibly benefit from employing OTs. In my experience they are extremely well-equipped to support people returning to work or joining the workforce for the first time.

### **3. Integrated services**

Integration of services can be seen on two levels

1. how specialist services need to work together- and often don't
2. having more integrated, holistic service providers with a range of options under 'one roof'.

The importance of service providers working together is being stressed over and over again. This includes clinical support, community-based NGOs and job service providers. It can lead to great outcomes for our clients, but is usually a complex task and many people do not feel equipped to work well on inter-agency levels. Referrals are often enough cited and recommended, but in my

experience with little awareness or expression that it can be a very complex and time-consuming process.

An aspect that does not appear in policies, guidelines, evaluations or reports is the human factor of organisations working together for our clients. Sometimes the shortfalls and lack of communication are related to nothing other than interpersonal problems within or between services. However, when local networks are funded, facilitated and funding bodies express a clear expectation of attendance they can be useful. They provide the ongoing flow of information about 'what services are available and who is the person in the position that I need to talk to. This is especially useful in an area such as Darwin where the staff turnover in most positions is high. It can also help to overcome prejudices and personal problems between providers.

I would like to talk about another way of having integrated services. My work as director of a Clubhouse has given me great insight into the benefits of an integrated service model. A Clubhouse is a day program for people with mental illness who are members rather than clients. They are seen as the 'owners' of the Clubhouse, work in partnership with staff and are involved in decision-making on all levels. Members and staff work alongside each other on tasks, which are 'real', because they contribute and are essential to the functioning of a Clubhouse. This provides a great opportunity to genuinely work from a strength-based perspective. The work is meaningful and relevant and work opportunities have to be available for any level of participation. The skills and abilities of members are needed to keep all operations functioning: a kitchen, a garden, an office and an employment support unit. In my experience working alongside a person over a period of time provides insights that are difficult to capture in clinical assessments. Being needed and appreciated increases members' confidence in their skills. Establishing a work-ordered day and an ongoing celebration of achievements especially in work and education creates a culture of work orientation. Other dimensions of recovery are also strongly facilitated by the Clubhouse model:

- Social connectedness and support and a sense of belonging

- Genuine empowerment
- Capacity building and work readiness
- A diversity of stepping-stones towards employment
- Ongoing support for people who are employed

Regardless of what service we offer, I would like to briefly discuss another dimension that assists people in returning to work. Individuals usually develop relationships to people, not just to services or programs. To achieve good outcomes, people we service have to develop *trust* in staff and sometimes organisation. When I ask people who else they are involved with or which organisations assist them, they usually know the person and mostly the organisation, very rarely the program. It's not only *what* services we offer. It is also the *way we relate* to people.

This is partly determined by our own attitudes, but also by what our funding allows us to do: do we have integrated services or do we specialise and have to 'refer' people to yet another agency? The recent developments in FaHCSIA-funded mental health programs are a great example how a department has taken notice of what service providers at the grass roots experience. The guiding principle is the need of the family, not how they fit into criteria. With extreme flexibility in each program and between different funding streams service providers can be as creative and responsive as realities dictate.

#### **4. Challenges of staying in the job**

*"When he comes home from work, I need to debrief him, every day. That's an important part. I give him time, he just comes when he feels like it, but I really have to be there for him. He doesn't want to go to counselling and he doesn't even know that I am supporting him, but I am watching out all the time. I am observant of the triggers and I keep an eye on the medication."*

This comment of a mother and carer gives us an insight that ongoing support for many people with mental illness in the workplace is crucial. The levels of support fluctuate: from person to person and from time to time. From a service provider

perspective this level of ongoing support is hard to capture and often not seen as priority. In my experience this 'maintenance' is at least as important as 'getting the job'. I have seen people in and out of jobs many times if this support was not available and usually the person blames him/herself. They get increasingly discouraged or frustrated. Alternatively the boss or colleagues are being blamed for being unsupportive, idiots or other something else.

If the underlying issues, such as failed communication, unnecessary stressors or workplace flexibility are not being addressed, they often inevitably occur again and again.

When I worked in employment support we often found that people start very enthusiastically and are busy learning the job. After about 10-12 weeks, when challenges arise or just because the first excitement is over, people often had increased need of support. This included more frequent visits at their place of employment, liaison with employers and encouragement.

I have also encountered that people with mental illness have had many negative previous experiences in work places. Some of them are possibly be due to incongruent behaviours they might have displayed in the workplace during episodes of illness. However, the real experiences of bullying, ostracising, not 'fitting in' and dismissal are often traumatic events for people I have worked with. Problems at work can bring up emotions related to those events again and need to be addressed. An assessment of a person's previous work history, which includes knowledge about reasons for termination of employment can be useful.

Another aspect which is sometimes overlooked is the kind of employment we offer to people with a mental illness. Research and personal experience show that sometimes having no job is better than a position the person feel degraded by or which has a negative workplace culture.

For some people it is simply important that friends are family are not judgemental. One woman describes her ongoing battles with staying at work in this way:



*"It takes so much work to stay in the job, so much energy, that the rest of your life is just sapped of energy. But I still chose to work and instead buy things that make my life easier, a dishwasher, a robot vacuum cleaner, a woman who cleans my place every week. I don't cook for myself because I don't have the energy. Sometimes even my friends say, that's a luxury, you live on your own, why do you need someone to clean the house, why do you have a dishwasher, why do you buy take-away all the time? But for me it's a necessity."*

## **5. Role of families**

The importance of family and other social support has been increasingly recognised thanks to the ongoing work of carers organisations and carers legislation. The particular situation and needs of mental health carers have been described extensively by two important reports, which were funded by FaHCSIA, the "Mental Health Carers Report" and "From Adversity to Advocacy".

In the past families were sometimes seen as an obstacle to recovery and holding people back from progressing to employment. Recent research and the experience of many who work with families affected by mental illness establish the importance of family and other social support. Shankar and Collyer from the University of Sydney and Charles Sturt University point out the importance of vocational support providers working with families. Families and close friends can provide knowledge and experiences of a person's abilities, work history, strengths and limitations in a way that can only be established with close and ongoing contact.

A mother of a son with an undiagnosed mental illness airs her frustration:

*"He goes to these assessments and because he can present himself well, nobody thinks that anything is wrong with him. Then they get him to apply for jobs and he often gets them. But after a short time, they see what really goes on and they don't want to keep him and he gets very upset. I could tell them all the things that he has problems with from the beginning."*

At the same time they point out how information provided to families and friends can enhance the relationship and reduce anxieties of carers.

Another statement of one of our carers

*"Now that I understand the illness of my husband better, I think I can support him better when he goes back to work. I was getting frustrated that everything takes so long. But the psychologist explained things to me and I feel we can tackle it now."*

## 6. Campaigns for change

*"Our society only really recognises when you have a work identity. If you are deprived of that, that's very hard."*

*"I think it's good to see role models of people with mental illness working in all kinds of positions. We only see them stacking shelves at Woolies or crazy artists."*

*"I met a guy on the plane recently when I flew to Adelaide. He asked me what I do and I said I work in mental health and he said, "Look, I am an employer of a big company. If I would find out that one of my staff had a mental illness, I would get rid off them as quickly as possible."*

I think we all acknowledge that positive change is happening already, but also that more needs to be done. On a large scale, the work of many organisations and individuals over recent years have attributed to great changes in our perception. The work of Beyond Blue and Black Dog Institute show that ongoing education and clever marketing can make a huge difference.

I would like to see a similar movement for psychotic illnesses. The fear of people with mental illness and many of our stigmatising attitudes are mainly connected to psychotic disorders. Many people don't see anxiety and depression as mental illness any more; they are just depression and anxiety disorder.

*Personality Disorders, they are not even included in MHA Act*

I would also like to see carers and consumers not just recipients of services. They need to be involved as agents for change and development. In many areas their

value as educators, informants of policy and speakers is acknowledged and funded. These things don't just happen in a vacuum and they need to be funded and facilitated. The Northern Territory has a fair bit more work to do in this area.

*Adherence to National MH Standards*

Last but not least, I hope that we will have services and people in those services who adopt a truly strength-based attitude and a real understanding and belief in people's recovery of which work is just one aspect.

I would like to close with a statement of a consumer, who cannot be here herself, because she is at work and her employer does not know any thing about her mental illness

*As a mental health consumer who is currently in permanent employment in a full time administrative job in the health sector, I feel I am qualified to report to this parliamentary inquiry. My mental health history is that of numerous psychotic episodes, beginning in my mid-thirties. I re-entered the workforce approximately six months ago, and my current employer knows nothing of my history of psychosis.*

*In order to get myself job-ready, I attended a program offered by Carers NT, a public speaking course, which boosted my confidence enormously. I also accessed the services of the Commonwealth Rehabilitation Services, who helped me with updating my resume, targeting particular employees, and interview techniques.*

*I believe that in order to be ready for employment, the social disadvantage experienced by Mental Health Consumers needs to be taken into account. Consumers need to be built up socially so that they have a good foundation from which they move into work.*

*We need to ask many questions if we want people to participate in the workforce:*

*Is their life enjoyable? Do they feel motivated for recovery, growth, productivity, and financial reward?*

*Are they dealing with depression and anxiety apart from their other mental illness?*

*Have they experienced verbal aggression, emotional abuse, trauma, domestic violence, sexual assault, incest, violence, addictions, financial hardship?*

*Are they exercising? Eating well? Do they have enough money for fruit and vegetables?*

*Do they feel cared for? Loved? Close to others?*

*Are we **really** taking recovery as a consumer-guided, holistic process?*

*Science and medical treatment is only half of the story. The other half is the art of life itself.*

*Too much value is placed on the importance of work - by politicians and in general by the middle class. But we should appreciate a person not only because of the work they do. We should judge them also by how they treat other people and take into account how other people have treated them.*