GRACE GROOM MEMORIAL ORATION

PROFESSOR MIKE SLADE

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Thank you for your kind introduction. Chair of Mental Health Australia, Ms Jennifer Westacott, CEO Frank Quinlan, members of Grace Groom's family, other distinguished guests, ladies and gentlemen, good evening.

Can I start tonight by acknowledging and celebrating the First Australians on whose land we meet. I want to pay respects to the elders of the Ngunnawal (nunna-wol) and Ngambree (na-gambree) peoples past and present. I also acknowledge all indigenous Australians present here tonight.

Hello everyone. It's a huge pleasure to be here, and I'm honoured by the invitation to give this oration. My name is Mike Slade, and although I'm based in the UK I have many ten-pound pom relatives scattered across your lovely country, so it's always a joy to be back here. Each time I visit I enjoy checking who's prime minister at the moment, so well done Australia for keeping me on my toes.

My work in London involves leading a research team investigating recovery and well-being in the context of mental health services, and I also work as a consultant clinical psychologist in a community forensic mental health team, providing cognitive behavioural therapy to people experiencing psychosis who have a history of contact with the criminal justice system.

So I guess I've been invited because of academic expertise, but I have to say that much of what I've learned has not been through scientific research but through absorbing the wisdom of people who have been there and got the T-shirt. That is to say, people with lived experience of mental ill-health and its impacts.

My first experience of the mental health system was when I was 14. I signed up to do voluntary work, and was allocated to a local learning disability hospital. When I arrived, I was met at reception by a nurse and taken to the back ward where I would be volunteering. She led me in, and the first person I saw was a patient sitting on a couch and masturbating. However, she ushered me past him, saying "Don't mind him, he's always doing that", and took me to a window looking into a padded cell, in which a man sat in a strait-jacket, repeatedly banging his head on the wall. I was being shown the star exhibit in the zoo. This experience shocked me at the time, but has come to shape my view of the world, that bad things happen to people who have no power and are shut away from the normal checks-and-balances on acceptable experience that most of us citizens take for granted.

So some of my learning has occurred just through exposure – sometimes literally! But we are entering a new era, in which people with lived experience are finding a voice. I remember 15 years ago meeting a chap in London who was using mental health services. He told me how he preferred to be confined by a strait-jacket rather than the 'chemical cosh' of medication. I was shocked at this – who would choose to be physically contained like that? Then he said something that changed me:

> *At least with a strait-jacket, you can take it off and it's gone. When you stop taking medication, it's still in you.*

I realised that the reason I instinctively assumed medication was better was to do with my need to feel non-controlling, and this person had different preferences. The reality is that people are complicated and idiosyncratic, and there is no invariant solution to complex human problems. Some people prefer one form of support, others another. This is how it should be, and any system that makes choices for people who could with support make their own choices cannot be the best system.

Most excitingly, in recent years we are finding the voice of lived experience becoming more visible in shaping mental health systems, and in wider social and political debate. More of this later.

So, as I say, it’s an honour to be asked to give the Grace Groom Memorial Oration. Dr Grace Groom was an influential former Chief Executive, and people who knew her have described to me her determination, vision, passion, strength of character and sense of humour. She oversaw landmark reports in the history of mental health services in Australia, including Out of Hospital, Out of Mind in 2003 and Not for Service two years later. As we are now ten years on from Not for Service, it is fitting to open my remarks with a quote from this report. Not for Service is sub-titled ‘*Experiences of injustice and despair in mental health care in Australia*’, and the opening quote is from a consumer in Victoria:

> *I think for those who are severely ill and are isolated in the community due to their illness they often have no form of support even from family or friends. For people like that they are in the community living like ghosts – they are dying alone.*

Dying alone. Makes you think, doesn’t it? Who would want that? This illustrates one of the themes I will cover tonight.

A central challenge in mental health systems is viewing and relating to consumers, and family members, as being fundamentally similar to the rest of us, rather than fundamentally different. Most of the goals of people living with mental health problems are pretty similar to the goals of anyone else. I remember working with a client who, when I asked what their goals were, unusually he was able to articulate them very clearly. I should mention most people I see for therapy have been deep in the mental health system for many years, so the more common response when I ask about their goals is “I don’t know, you’re the doctor, you tell me”. So returning to this client, he was able to enumerate his goals very clearly – he wanted his own home, a job, a girl-friend, a holiday, and for his voices to stop verbally abusing him. Fundamentally similar with some differences due to mental health challenges, rather than fundamentally different.

Yet health services emphasise difference. Research published last year in the Lancet Psychiatry journal shows that stigma against mental illness is alive and well in health professionals. Stigma against people with mental health problems is also of course present in the general population, but it reduces following social contact with someone who moderately disproves the negative stereotype. National stigma campaigns and initiatives, such as Beyondblue and Mindframe in Australia, Like Minds Like Mine in New Zealand, See Me in Scotland and Time to Change in England improve community attitudes. By contrast, meeting people living with mental illness does not decrease stigmatising attitudes in health professionals. In-system stigma which emphasises differences between ‘them’ and ‘us’ is present in health systems, and not improving in line with more accepting community attitudes.

This may be why the so-called Friends and Family test is increasingly being used in my country to evaluate health services. The test is simple – would you recommend the service to your friends and family if they needed care or treatment? The reason it is becoming so widely used is because it cuts right through one of the core problems of health services. The old test was whether it was a good enough service for ‘them’ – those other people over there with that diagnosis, who are different from me. The Friends and Family test asks whether the service is good enough for me, for us. It reminds us that people with mental health problems are people, just like anyone else in society. So if our hopes and expectations for them are lower, that is because we hold stigmatising views.

Returning to the *Not for Service* report, it outlined concerns about violations of the basic human rights of people with mental illness. These were much the same concerns as described in the earlier Burdekin report, published in 1993. What is the situation now? In July this year, Mental Health Australia along with 97 other organisations wrote an open letter to Australia’s First Ministers. They referred to the National Mental Health Commission report chaired by Professor Allan Fels, which identified problems of poor planning, coordination and operation between the Commonwealth and the states and territories, resulting in duplication, overlaps and gaps in services. The letter went on to argue that Australia's mental health crisis has deepened in the past two years.

So what can I suggest?

First, it can be helpful to realise that, as a country, you're not in this alone. In England, for example, we are grappling with the shocking statistic that people with mental health problems die around 20 years younger than other citizens. The 2012 Health and Social Care Act stated that equal priority should be given to mental and physical health, Yet last year, the Department of Health in its report *Closing The Gap* recognised that '*things are not changing fast enough*'. It identified as a first priority for action that '*High-quality mental health services with an emphasis on recovery will be commissioned in all areas*'. Which brings me to recovery.

Recovery has become a banner term for an international movement which aims to transform mental health systems and society.

What does recovery mean? The everyday meaning of 'recovery' is getting back to normal, and this represents what we might call the surgical metaphor in health. In this narrative, you're fine to start with, then you sustain an injury, you take the treatment or have the surgery prescribed by the expert clinician, and then you get back to normal. This narrative has been incorporated into the mental health system: do what we – the experts in the system – tell you to do and you will be well again. For some people this approach works wonderfully. The person receives a diagnosis which makes sense of their difficulties, they take the prescribed treatment, they feel better and they move on with their lives. Many people are alive and flourishing today because of the efforts of knowledgeable and caring clinicians. However, there are cracks in this narrative. When we listen to what people with personal experience of mental illness and recovery tell us, we find that some people identify that their recovery was nothing to do with the mental health system, but rather to do with spiritual re-awakening, or re-connecting with their family of origin, or learning to love themselves for the first time, or letting go of pain from their past. For example, Ron Coleman is a Scottish consumer trainer and consultant who runs the company Working to Recovery, and he says that his recovery began when, at his first Hearing Voices group, someone told him his voices were real. Even worse, some people report that they recovered despite the mental health system. For example, their voices represented their childhood abuser, yet clinicians insisted on asking "What's wrong with you?", when they should have been asking "What's happened to you?". I remember a lady who was referred to me for treatment-resistant depression. She had been tried on various anti-depressants, with no benefit, but as I got to know her, she disclosed that her husband was beating her up. She was indeed depressed, but viewing that experience through a treatment lens was toxic.

The new understanding of recovery which has emerged internationally focuses far more on the experience of living. The most widely used definition comes from Bill Anthony, who defined recovery as '*a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and roles*' and as '*a way of living a satisfying, hopeful, and contributing life even within the limitations caused by illness*'. In my service, we use a shorter definition that recovery involves '*living as well as possible*'. This reminds workers like me that the efforts of people experiencing mental ill-health to live as good a life as possible are just like our own efforts to live as well as possible despite our life challenges. We are all in this together.

Where has the recovery movement come from? I think there are three narratives about its history. The first narrative is that ideas about recovery have come from people with personal experience of living with mental illness. People are increasingly wanting to tell their story; to speak and be heard. In recent years there has been an avalanche of books, web-sites and other repositories of these narratives, and they provide a powerful counterbalance to professional views about mental illness. This is great news, because mental health systems have reached something of a dead end in their pursuit of the magic bullet. The various typical and atypical antipsychotic medications, psychological therapies such as cognitive behavioural therapy and dialectical behaviour therapy, early intervention and assertive outreach – all of these treatments and service models help some people some of the time, but they are not invariant solutions, and for some, they are not solutions at all. We need fresh thinking. In the words of consumer activist Priscilla Ridgway:

> *We need to reach beyond our storehouse of writings that describe psychiatric disorder as a catastrophic life event*.

The collective voice of people with lived experience gives us this new knowledge. My research has been particularly concerned with synthesising what we can learn from people with lived experience. We conducted a systematic review of the global literature about what's involved in recovery, leading us to develop the CHIME Framework. This describes the processes which we find occurring in many people's recovery journey, and it stands for Connectedness, Hope, Identity, Meaning and Empowerment. Supporting these processes has not consistently been the focus of the mental health system. For example, connections with family, friends and a community of our own choosing are central foundations for a good life for most of us, yet the mental health system has created ghettos in which people with mental health problems are cut off from these normal relationships. In the name of protecting these vulnerable people, we first created what Goffman called total institutions, asylums to separate 'them' from 'us' and in which people lived and died. Patricia Deegan's cemetery restoration project in Massachusetts involved reclaiming 30,000 cemeteries containing graves of inmates of the Central State Hospital which are marked only with a number. More recently, developed countries have closed most of these long-stay asylums but inadvertently created in their place 'virtual institutions', in which consumers apparently live in the community but in fact live in a mental illness-defined bubble, in which the people they live with, work with, meet with are all part of the mental health system, and in which the opportunities to be an everyday citizen can feel non-existent.

The second narrative describing the development of recovery as an idea talks about changes within the mental health system. Epidemiological research is concerned with what happens to groups of similar people over time. New long-term epidemiological studies are finding that recovery is possible for more people than we thought. For example, the AESOP-10 study published this year concluded that:

> *The research relating to outcomes in schizophrenia and other psychoses, conducted before the more recent long-term course and outcome studies, has painted an overly pessimistic picture of the clinical course*".

So it turns out that hope is an evidence-based attitude, yet hope-impoverishing practices in the mental health system still persist. For example, some staff encourage what is euphemistically called 'realistic expectations', but really means 'low expectations', when they tell consumers not to expect to work again, or not to expect to live independently. These kind of statements, though benevolent in intention, are toxic in their hope-destroying effect. They are also non-scientific. For example, rigorous scientific research involving randomised controlled trials in many countries has investigated the Individual Placement and Support or IPS approach to helping people with mental health problems to get a mainstream job. This research shows that the concept of 'work-readiness' – having to prove that one is ready for a job – has no validity. The best way to learn the skills needed for a job, just like for anyone else in society, is to get a job, and then with support learn to do it well. Similarly, the positive findings from the At Home / Chez Soi initiative evaluating Housing First approaches in Canada has shown that supporting people to obtain and keep a tenancy in mainstream housing is much more effective than preparing them to be good tenants.

This is part of a bigger pattern of change, in which the old beliefs, that the system sorts the person out so they can get on with their life, are being systematically undermined by scientific research. What we find is that the best way to help someone with mental health problems to have a good life is to support them to get into life, not to prepare them for life. Developing mental health-specific solutions to mainstreams problems can get in the way of someone's recovery journey. So for example, during my clinical training I was taught that a good response to someone with mental health problems saying they want a relationship is to offer social skills training. I now know that a better response is to help them get out into the work-place, have a social life, go on speed dating events, use internet dating sites, the normal things single people do to find love.

The third and most challenging narrative about recovery is that it is part of what is called identity politics, aligned with other forms of social justice movement. We know that real progress has been made in challenging discrimination against many groups in society. In the case of wheelchair users, for example, in England it would now just be socially unacceptable, as well as illegal, to tell someone they can’t work here because they’re in a wheelchair and the building has stairs. The need for workplace adjustments for people with physical health problems is universally accepted. Anti-discriminatory practice in relation to employment lags behind for mental health, with many employers simply unclear of the work-place accommodations needed to allow people with mental health problems to work. In other areas of life too, the battle for equality is well advanced. Mary O’Hagan is an internationally-renowned recovery champion from New Zealand, who previously used mental health services and went on to become commissioner for the national system. She had an early interest in three areas of discrimination – gender, sexuality and mental health – and she decided to focus her efforts on mental health. Reflecting on her career, and the tangible advances in women’s rights and gay rights but the markedly slower progress in relation to mental health, Mary told me she had concerns she might have “*backed the wrong horse*”.

If the battle for equality is well advanced in other areas, why not in mental health? I think it’s to do with power, and the way societies change. The hard reality is that power is never given, it’s always taken. In England, Parliament gave equal voting rights to women and men in 1928. But it was the suffragette movement, involving activists like Emily Davison who was killed when she threw herself under a horse belonging to King George V at the 1913 Epsom Derby, which led to this change. Women were not given the right to vote, they took it – through having a voice, arguing the case, and – sometimes – through direct action in order to get heard.

This is why the recovery movement is so exciting. There have been other movements in the history of mental health – institutionalisation, de-institutionalisation, community care, social psychiatry – but what these all have in common is that they involved one group of people deciding what's in the best interests of another group of people. The recovery movement is the first time that people directly affected by mental health problems are themselves involved in the debate about their own future. The civil rights movement mantra of 'Nothing about us without us' applies just as much to people with lived experience of mental illness as to any other group in society. Why wouldn't it?

All of this points to the need for transformation within and beyond the mental health system.

One aspect of transformation is updating what we believe in the light of new evidence. In July this year, MI Fellowship published a report bringing together the scientific evidence about mental health and recovery. It was written by myself and my colleague Eleanor Longden, who is open and passionate about her own lived experience of trauma, dissociation and psychosis, skilfully fusing her expertise by profession as a postdoctoral psychology researcher with her expertise by experience. In the report, we tackle head-on some of the implicit assumptions which can be held in the mental health system. Instead of recovery being best judged by experts, we made the case that it is best judged by the consumer. Instead of the view that few people recover, we made the case that many people recover – it's just that services don't see them. Instead of the view that treatment is necessary, which justifies compulsion, we made the case that treatment is one route among many to recovery, implying a much more tentative approach to treatment. The report uses two forms of evidence – knowledge based on research involving groups, and the new knowledge which is emerging from individuals with lived experience. Why do we need to consider the stories of individuals? Because if we only listen to professional constructions and narratives, we inadvertently oppress. In the words of Chimamanda Adichie:

> *Stories matter. Many stories matter. Stories have been used to dispossess and to malign, but stories can also be used to empower and to humanize. Stories can break the dignity of a people, but stories can also repair that broken dignity.*

At the clinical level, this means workers valuing not only their professional expertise but also the expertise of the consumer – in other words, fully recognising that there are two experts in the room. But what does this new knowledge mean for services?

Over the past few years, my research group have been focussed on identifying and supporting transformation of services. One output has been a synthesis of international best practice in supporting recovery. Published in 2011, the framework has informed policies internationally, for example your *National Framework for Recovery-Oriented Mental Health Systems* published by the Australian Mental Health Ministers' Advisory Council in 2013. The framework identifies four areas of action for mental health services.

First, supporting personally-defined recovery through the competent and available provision of effective treatments and interventions. The key here is that treatments are offered as a resource to people in their recovery journey, rather than done to them in their best interests. In other words, services on tap, not on top.

The second area of action is in the basic relationship between the consumer and the worker. In England we have a national transformation programme called Implementing Recovery through Organisational Change, or ImROC. In their words, transforming services "*depends on changing basic, everyday interactions between staff, service users and carers*". To support this, we have developed and evaluated a new intervention called REFOCUS, which involves training psychiatrists, psychologists, nurses and other workers to use coaching in their work with consumers. Coaching has helpful pro-recovery assumptions that the coachee – the consumer in this case – has the expertise and skills to find their own solutions to their problems, providing they get the right kind of support from their coach. The REFOCUS intervention is now being tested in the PULSAR study in Victoria.

The third area of action is organisational commitment, and involves top-to-bottom transformation of the mental health service. The ImROC initiative I mentioned earlier works at this level, supporting mental health systems across England to grapple with these challenges. And real challenges they are – whether it is organisational concerns that they will be pilloried in the press if a tragedy happens involving someone on their books, or the worker concern that they will be hung out to dry if they support positive risk-taking and – as sometimes will happen – things go wrong. One important lever of change at the organisational level is the development of peer worker or consumer-provider roles, which involves jobs in the mental health system for which lived experience is an essential job requirement. Peer workers act as credible role models of recovery for other consumers, and a systematic review by the internationally-respected Cochrane group found that they have an equivalent benefit to non-peer case managers. In England, the ImROC transformation challenge is that 50 - five oh – percent of the approximately 100,000 mental health work-force will comprise people with lived experience. One vehicle for this change in the work-force is Recovery Colleges, which now number 32 in England and are starting to open in Australia. Recovery Colleges employ peer trainers to co-produce and co-deliver educational courses for mental health consumers, family members and staff, and will I believe prove to be a vehicle for mental health system transformation internationally.

More generally, I’ve visited mental health services around the world which have fundamentally changed their work-force to include a large proportion of people with lived experience, including traditional services which through inspirational leadership have re-invented themselves, such as Recovery Innovations in Phoenix, or innovative peer-run services such as the KeyWeWay recovery and crisis service in New Zealand. They are amazing places in which stigma has no home – if you like, the wall-paper is different.

These services illustrate the paradigm shift in a recovery-oriented mental health service, from viewing lived experience as being part of the problem to viewing it as part of the solution. This is good for consumers, as it offers the opportunity to transform from a damaged identity to someone whose lived experience gives gifts of compassion, creativity, self-awareness or authenticity, as well as the chance for work and a resource with which to help others. But this paradigm shift is also good for professionals, who can so often feel trapped by unmeetable expectations and too distant from the caring motive that first brought them in to mental health work. In the words of Mark Twain:

> *When we remember we are all mad, the mysteries disappear and life stands explained.*

When as a worker your assumption is that the consumer has strengths, you move from thinking it’s your job to fix their deficits and instead become curious about how their strengths can be activated, leading you to develop skills in appreciative inquiry. When as a worker your assumption is that recovery is a subjective experience that starts with hope, you realise you need your peer worker colleagues who can be inspiring and hope-promoting role models. When as a mental health system you’re grappling with socio-political expectations that you will contain the madness in society, and you see how that creates defensive and recovery-inhibiting clinical practice, you start considering whether the problem of risk is partly a social construction, and whether the solution therefore might be societal change, and whether you may need to partner with consumer activists to achieve this. In short, you begin to make sense of the words of the Brazilian political activist Paulo Freire:

> *Only the power of the oppressed is sufficient to liberate the oppressed and the oppressor.*

The final area of action for mental health services, and the one which in my view has the biggest potential pay-off, is at the level of promoting citizenship. Living well for most of us does not happen in the hospital or in mental health service settings. It happens as we live our lives in our chosen community. Living well happens when people celebrate and use their strengths rather than trying to pass as ‘normal’, when people have the combination of self-management skills and the right support from others to be able to make choices about their own life, when they access inclusive and welcoming communities which are friendly to difference. Or to put it another way, a good life for people with mental health problems, just like a good life for the rest of us, happens when anticipated or experienced discrimination does not hold someone back from leading a life of their own choosing, subject only to the societal constraints imposed on any other citizen.

What does this grand vision mean for mental health services? It means that we need to move from a treatment-based model to a citizenship model, in which the core business changes from providing effective interventions to supporting people to make their way in the world. I mentioned earlier that employers often don’t know what work-place accommodations to make for people with mental health problems. This is because workers like me are trained and expected to spend their time working with individual consumers. Perhaps a better alternative would be for people with professional training to spend their time trying to support employers to make mainstream jobs available? And perhaps an even better alternative would be for a worker like me to partner with a peer worker with lived experience, so we can together support that employer? Down the line, we might even become ambitious enough to set up a peer-run service for employers, like the Mental Health at Work organisation in Melbourne.

And we can do more. We need workers to provide effective treatments for those who want them, but if the big gains are to be made in society and not in clinical spaces, then maybe we need to re-imagine the role of the mental health worker. Because poverty and socially unequal societies lead to mental ill-health, because abuse experiences can lead to psychosis, because experiences of discrimination can be worse than the illness itself, a re-imagined role for workers would involve not just being aware of, but acting upon, the social determinants of mental ill-health. In such a system, professionals and peer workers would spend some, perhaps much, of their time supporting and engaging in societal change, working with mainstream groups to develop more inclusive communities.

And in line with the civil rights movement call to ‘Fix Society, Not People’, political action would also be part of the job. Many countries have structural discrimination at the political level which disenfranchises people with mental health problems. For example, in England it was only two years ago that the Mental Health Discrimination Act of 2013 repealed section 141 of the 1983 Mental Health Act, under which Members of Parliament detained on grounds of mental illness could be made to vacate their seats, although someone incapacitated due to physical health reasons could not. I was therefore delighted when one of the clients I work with decided to stand as a candidate in an election. I was meant to be giving him cognitive-behavioural therapy for psychosis, but in reality we discussed his manifesto, his experiences of speaking at hustings, and his engagement in the political process. Was my work with him therapy? Perhaps not. Was it supporting his recovery? I believe so.

More generally, who has a voice? Let me illustrate this in relation to scientific conferences. I organise an international recovery research conference every two years in England, called *Refocus on Recovery*. We typically have four to five hundred participants from over twenty countries. We have a requirement that at least half of the key-note speakers have lived experience, as must half of the Scientific Advisory Board, who decide which submissions to accept. In recent years I get increasingly approached to give conference talks in different countries. I now respond by asking whether there is a lived experience speaker in an equivalent role. For some conference organisers this is a new idea, which gives the opportunity for helpful discussions about how this benefits scientific conferences.

In closing, I believe we would see meaningful societal shift if people in positions of authority and power consistently used that position to give voice to people with lived experience. If it became the norm for our clinical training programmes to involve peer trainers in every aspect. If professional development courses were jointly developed and delivered by clinical trainers and peer trainers, for example through Recovery Colleges. If media interview requests about mental health services were always responded to with the suggestion to also include someone with personal experience of using those services. If mental health services and systems partnered with empowering consumer organisations like Mad Pride and the International Hearing Voices Movement to challenge discrimination at every level of society. If, in short, ‘nothing about us without us’ was the reality experienced by people living with mental health problems.

I thank you for your attention.