Mental Health Council of Australia

Grace Groom Oration

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Welcome and thanks

Good evening and welcome.

I am Jennifer Westacott, the Chair of the Mental Health Council of Australia.

It gives me great pleasure to welcome you here this evening. I feel very privileged to have been asked to deliver the 2013 Grace Groom Memorial Oration as part of Mental Health Week 2013.

I wish to thank the National Press Club for hosting this event.

And to thank the ABC and especially Lyndal Curtis for helping to facilitate our event.

Acknowledgments

Before I begin, I wish to acknowledge and celebrate the First Australians on whose traditional lands we meet. I want to pay our respects to the elders of the Ngunnawal (nunna-wol) people past and present.

I would also like to acknowledge the Minister for Health, Peter Dutton, who has just taken portfolio responsibility for health and mental health.

The Minister has kindly agreed to speak tonight and then join us for the panel session.

I would like to acknowledge Senator, The Honourable Jacinta Collins, former Minister for Mental Health, and Senator Penny Wright, Greens spokesperson on mental health.

Finally, can I acknowledge Professor Alan Fels and Georgie Harman from the National Mental Health Commission, and thank the MLC Community Foundation for their ongoing support.

Grace Groom

This event recognises the outstanding contribution of Dr Grace Groom to the Mental Health Council of Australia and to the cause of improving mental health services for all Australians.

Dr Groom was a former CEO of the Council and left an indelible mark on the mental health sector in this country.

Her vision, determination and strength of character led to landmark reports such as Out of Hospital, Out of Mind and Not For Service. These reports highlighted significant problems with individual experience in mental health care in Australia.

So I would like to take this moment to acknowledge Grace and the members of her family in the audience - Nouri (nor-ee) Groom and Nicole New.

It is interesting to briefly look back at that moment in history when Not for Service was released.

On the ABC radio program PM on Wednesday, 19 October 2005 - almost 8 years ago to the day - Mark Colvin introduced a segment on the launch of the report as follows:

'In 1993, shamed by the swingeing recommendations of the Burdekin Report on Mental Health, Australia's State and Federal Governments promised to do better in every respect[i]. Today twelve years on, comes an equally damning report showing that little has changed.'

Earlier this year, a report led by John Mendoza, another former CEO of the Mental Health Council of Australia, detailed disturbingly similar findings:

The Mental Health Council of Australia also recently released a report called "Perspectives". While it details some of the elements of a future vision for mental health in Australia, it is an indication that we still have a long long way to go and we lack a coherent plan to get there.

I think it is fair to say that if Mark Colvin were to cover our story today he possibly would have little reason to change his script.

This is despite successive governments making periodic significant investments, creating new dedicated bodies to progress reform and, of course, acknowledging the need for major reform.

But, for of those who experience mental illness, their carers and their families, the pace of change is too slow.

After decades of reform, the reality on the ground falls way short of what they need. Worse, in some cases it produces a series of debilitating set-backs.

This presents a challenge for me - indeed for all of us.

I would like to think that we would be able to look back in less than 10 years and regard Not For Service and other such reports as a measure of how far we have come.

The Focus of My Speech

In that spirit I want to cover a few themes tonight:

- The first is - why I took this role and my personal commitment to it

- The second is to outline some of the Council's recent thinking on a vision for mental health in Australia and some of the shifts needed in the way we prioritise and deliver services

- And thirdly, I want to put forward some ideas for a fundamental rethink of attitudes towards mental health in Australia.

- I want to present a call to arms for a movement for social change and acceptance.

My Personal Journey

So, to why I took this role.

When Rob Knowles and Craig Knowles called me to ask me if I was interested in this role, I barely had to think twice before saying 'yes'.

I have a deep personal commitment to this issue.

In my own life I have been touched by poverty and exclusion.

I have also seen people close to me living with mental illness, discriminated against and rejected. Despite this, they have used everything in their power to overcome their illness and to make important contributions to society and to their families.

I know that most people in the community have been affected by mental illness in some direct or indirect way. And I know that many people in this room have been deeply affected.

My second reason is a professional one. I worked in some of the most difficult areas in government. In the Department of Housing, in the Department of Community Services, in Health and in Education.

I saw time and time again, people experiencing mental illness – be it severe or mild – fall through systems often run by incredibly well intended people, hard-working people, committed people.

It seemed to me that the systems themselves worked against everyone involved. The services, designed to help, sometimes created a deterioration not an improvement in people's circumstances.

This was particularly the case in public housing.

For me and my family, our allocation of public housing was like winning the lottery. Stable and affordable housing, ultimately a place we could afford to own. A pathway out of certain poverty.

But for some people, particularly those experiencing severe mental illness, that allocation of public housing was the beginning of a long nightmare.

The wrong house, in the wrong place, at the wrong time in someone's life, without adequate support, led to untenable and sometimes catastrophic results for vulnerable people and their families.

In my role as Secretary of Education, I saw a good system failing to identify the early warning signs of mental illness in young people, failing to help them avoid high risk activities such as drug taking.

Activities that could trigger not just a one off episode but a life time of mental health issues.

In Community Services, I saw the inadequacy of a system designed to protect vulnerable children.

Failing to see the early warning signs. Failing to recognise the impact of trauma. Failing to see the combination of risk-factors, drug and alcohol, homelessness, mental illness - that were often a cocktail for complete disasters.

I saw how well-meaning but rigid privacy laws often limited agencies working effectively together to properly protect the people who needed protection. The people who had no voice of their own – children and young people.

In all these experiences, what I observed, was the inability to think about mental health services and disability services and many other aspects of social policy as integrated systems.

Systems that should be centred around the well-being of people and their families, not the rules and protocols of separate agencies. I remain committed to changing that.

My third reason for taking this role is that I believe passionately that business does, must, should, and can play an even more important role in issues like building a mentally healthy Australia.

At the most basic level, they will be the employers of many people experiencing mental illness or those caring for someone with mental illness.

But there is also much to learn and exchange between the public, private and non-government sectors.

Business understands systems. They understand consumers. They understand data and they understand costs.

While business is comfortable with the idea of risk, business has little appetite for wasted investment.

While we often think of businesses competing with each other, we frequently forget that business can be at its most profitable and at its best when it builds partnerships and joint ventures.

Combining capacity to achieve common goals is often the hallmark of highly successful businesses.

I am not suggesting for a minute that business is without faults.

But a society truly works when those three sectors – government, business and the non-government sector – come together in a compact to create a prosperous and fair society.

It is my intention to bring the best attributes of the business community to the Mental Health Council of Australia.

I will do this unashamedly.

The Council's Vision for Mental Health

The Council recently reviewed our strategic directions. Our vision is for mentally healthy people and mentally healthy communities.

Our mission is to create the best mental health system in the world. I believe we can do this in a decade. That system would be characterised by the following:

- It will be co-designed by consumers and carers
- It will be based on prevention and early intervention
- It will focus on recovery
- It will be based on participation and the realisation of people's potential
- And it will drive integration

If we are successful, in a decade, we will create a system which ensures continuum of care and an integration of all the services and opportunities that contribute to a meaningful life.

It will be a system driven by measurable outcomes and clear results.

It will be dynamic and responsive to evidence and change.

In simple terms, it will be a system where services, accommodation, employment and support, are designed around the needs of a person and their families and carers.

This will be in stark contrast to what exists now, where consumers and carers are forced to navigate through a labyrinth of complexity.

I know that there will be some cynicism about this. But cynicism to me is the enemy of action and the friend of inertia.

And if we look at the data, the business case for this decade of change is not only morally and socially compelling, it is economically fundamental.

Killer Facts:

I know that reeling off statistics can be boring, but in this case it is the best way to highlight the extent of the problem and remind ourselves of the extent of the challenges we face.

So here are some important facts:

- Collectively poor mental health accounts for the largest proportion of overall disease burden in Australia[ii]

- 45 percent of Australians will experience a mental health issue at some point in their lives and 20 percent will do so in any given year[iii]

- According to our friends at beyondblue, in any given year, around one million Australians will experience depression and around two million will experience an anxiety disorder[iv]

- Over 50 percent of people admitted to alcohol and drug treatment facilities have a history of mental illness[v]

- Just to amplify my point about the complexity of the service system, the National Mental Health Commission's 2012 Report Card, estimated that around 900,000 Australians are missing out on services that could benefit them[vi]

- In 2010, 2,400 people in Australia died by suicide. One estimate is that up to 50 percent of people who died by suicide would have been diagnosed with clinical depression at the time of their death[vii]

The next decade must be better than this.

And as if the moral and social case is not persuasive enough, the economic case is equally compelling.

- The ABS estimate the annual cost of mental illness in Australia is just over 20 billion dollars per year[viii]

- Recent research by the Nous Group and Medibank Private, estimates that the total expenditure on programs and service delivery related to mental health is much higher than we thought, including spending that would not be necessary if the system was working properly[ix].

- Australia has one of the lowest rates of employment participation by people with lived experience of mental illness in the OECD[x]

- Australian research suggests that mental illness in young men aged between 12 and 25 costs the economy over 3 billion dollars per annum[xi].

- This is shocking in economic terms, but it is even worse in respect of the loss of potential for these young men and their families and carers.

Directions for Change

I cannot imagine that anyone would question the veracity of the data I have just put forward or the urgency of the case for change.

The toughest challenge is the what, why and how of a decade of system reform.

So for me tonight, I am not just giving another speech about mental health. I am making a plea and a call to action to work together to get this right once and for all. I am, put simply, calling for another way.

I want to give you a brief snapshot of some of the themes I outlined earlier. Consumer and carer led design, prevention, recovery, participation and service integration.

I want to make some suggestions for how we could change our approach. These are by no means comprehensive but it will give you a sense of some our early thinking and we plan to engage as broadly as possible as we turn these themes into concrete plans of action.

Consumer and Carer Design

Our first platform for change is that carers and consumers must co-design the system. As we begin to conceptualise a new mental health system, the lived experience of consumers and carers must be a starting point.

We know from bitter experience in many parts of public policy that it is just too hard to retro fit involvement.

We easily concede that we need to empower people to tailor services to their needs and involve carers, families and consumers in decisions. Although we too often fail to deliver.

But we must also involve consumers and carers in the overall system design. In the programs, in the funding models, in the governance models and in the design of service delivery.

I need to be clear here, I am not talking about one off consultations, but a permanent continuous and deep involvement of consumers and carers in all decisions that affect them.

Some ideas for action

So, let me suggest some ideas for action.

We need to routinely survey and report consumer and carer satisfaction with all aspects of the system

We need to ensure consumer and carer peak bodies have adequate support and funding to allow representative and thoughtful involvement in the ongoing reform process

We need to ensure consumers and carers are represented at all levels of our governance and organisational arrangements, including having a place at the table when governments sit down to discuss these issues, and

We need to foster and build our peer workforce, of consumers and carers, to provide support as people journey through the system .

Prevention and Early Intervention

The second platform for change is prevention and early intervention.

Prevention matters

There are clear economic, health and social benefits to be gained from a greater focus on the promotion of good mental health and the prevention of mental illness.

People with lived experience of mental illness are more likely to experience exclusion from economic and social structures, including housing, education and employment.

It is estimated that up to 50 percent of people who go on to develop ongoing mental illness, first exhibit symptoms before the age of 14 and that 75 percent do so before the age of 25[xii].

Depending on the severity of symptoms, the impact on educational attainment and employment outcomes can be devastating.

According to the OECD, people who develop mental illness by the age of 18 are twice as likely to have disengaged from education and vocational training as their peers by the age of 20[xiii].

This is why a focus on the identification of both protective and risk factors for the development of mental illness and interventions that tackle both is important, especially in children and young adults[xiv].

Mental illness education in primary and secondary schools is one way in which awareness of the signs of mental illness could be promoted directly to young people.

Mental Illness Education ACT is one example of an organisation that employs consumers and carers to share their lived experiences with school students.

The program has been shown to increase help-seeking behaviour among young people.

We should contemplate a national initiative of this kind.

We should remain mindful that it is possible to intervene at any point to prevent things getting worse.

As well as spotting early warning signs in young people, we need to find ways to prevent the onset or progression of mental illness for people of any age and from any background, including Indigenous people, people from diverse cultural backgrounds and people at higher risk of mental illness.

What To Do?

So, what specific actions could we take?

Stigma remains a major barrier to effective prevention and early intervention. We need to fund a sustained national anti-stigma campaign, carefully targeted to reach particular populations and settings.

Our priority is to slow the flow of people into mental illness and deal with those most at risk

We need invest in a coordinated, sustained, national approach to suicide prevention, supporting Suicide Prevention Australia's partnership with the 20 organisations,

including the Mental Health Council of Australia, that are part of the National Coalition for Suicide Prevention.

We need to continuously evolve our online resources and interventions building on successes like Mindhealthconnect which makes online resources available from a single point of access[xv]

We need to ensure a series of integrated centres to assist particular targets groups by intervening early including:

- Maternal and early childhood centres to provide support at the earliest possible time through to early school years

- National access to headspaces and Early Psychosis Prevention and Intervention Centres to assist young people

- Roll out programs similar to the ACT initiative where carers and young people visit schools to talk about lived experience.

- And we need to gather evidence to identify and support similar initiatives for older Australians and other age groups

In addition to doing all we can to intervene early, we must also provide a hand up to those who have already fallen through the cracks.

This will require a sustained focus on physical health, housing and employment:

To close the gap on physical health, our priority should be to tackle targeted antismoking programs.

And we should also invest more research effort into metabolic syndrome in those taking anti-psychotic medication.

On housing, we should expand models of housing which embody wrap around services which link housing and support services together.

Recovery

Now let me turn to recovery. The concept of recovery has grown out of the mental health consumer movement and there is a strong sense of ownership of and commitment to it.

A key strength of the recovery movement is that it focuses on the whole person and the need to improve outcomes across the whole of a person's life.

The lived experience and insights of people who experience mental health illness and their families are at the heart of recovery-oriented culture.

The recovery focus has two dimensions, clinical recovery, of course, refers to a reduction in symptoms. But the aim of the recovery movement is for individuals experiencing a mental illness to achieve personal recovery.

Personal recovery is something only a particular individual can define. It is not something that a mental health practitioner decides for a consumer.

It is fundamentally about self-determination, self-management, personal growth and regaining hope and connectedness.

The challenge for a world class mental health system is to shift away from the traditional bio medical model to one that balances clinical recovery and personal recovery.

This requires a vastly more whole of life approach to care. It builds on the strengths of individuals. It requires partnership between health professionals and people with mental illness and their families.

Recovery fundamentally recognises that while mental health professionals have expertise in assessment and treatment, people with lived experience are experts in their own life.

So how do we turn a “recovery orientation” into practice? We must lay it like a blanket over all that we do.

We must all accept our obligation to create and foster an environment of hope and optimism.

This includes changing our public discourse to ensure mental health conditions and diagnosis are no longer used as insults or derogatory terms

We must re-imagine our services and programs to ensure they are comprehensive and person centred.

We must focus on personal strengths, and personal responsibilities, and opportunities for personal growth.

We must embrace the lived experience of mental illness in our organisations and in our workplaces.

We must begin with the individual, but must address the full spectrum of social determinants of health rather than tackling individual symptoms in isolation

In short – we must fund the national implementation of the recently published National framework for recovery-oriented mental health services.

Employment & community participation

I will turn now to employment and participation. I am sure you will not be surprised these are important priorities for me.

We know that people with lived experience of mental illness want the same work opportunities as other Australians.

Rates of volunteering and participation in unpaid work are also similar to that of the general population, but for paid work the story is much less positive.

Around 60 per cent of working aged people experiencing mental illness were employed in 2011-12, compared to 80 per cent of the rest of the community. Twice as many people experiencing mental illness were not in the labour force[xvi].

Recovery-oriented practice must play a vital role in boosting rates of employment participation by people with lived experience of mental illness.

The person-centred approach of recovery-oriented practice increases confidence and self-esteem and the ability to make determinations about future planning and goal-setting.

This is as fundamental to participation in the workplace as it is in other settings.

However, there is also much to be done on the employers' side.

Obviously, a key responsibility of all employers is to create mentally safe, healthy and supportive workplaces.

Many major companies that I work with are already undertaking some specific initiatives in this area.

A key part of employment participation is flexible job design.
While this will not work in every sector, surely it is not beyond us to create jobs and workplaces that can be more responsive to the reality of living with, or caring for someone living with a mental illness.

This will require more collaborative workplaces and more direct engagement between employers and employees.

Of course, every employer, large, medium or small, needs to be cognisant of the unintended consequences in how they handle major restructures and major change.

Badly handled, these can have devastating impacts on the entire workforce, not just people at risk of experiencing mental illness.

There is a compelling case for Job Services Australia to provide more tailored services for unemployed people with a mental illness and for the entire skills and job network to provide appropriate, more specialised, longer-term, pre and post-employment support.

But at the heart of participation in employment is the promotion of awareness and understanding.

It is extremely difficult for both employers and employees to create a supportive environment if there is no mutual understanding or worse, an environment where people don't feel safe to talk about their mental health.

This includes carers who equally need flexible and sympathetic work arrangements.

We should eradicate workplace bulling and relegate it to the pages of history, once and for all.

This is why the National Mental Health Commission, the Business Council of Australia, and the Mental Health Council of Australia, and many others have come together to create the National Mentally Healthy Workplace Alliance.

Our alliance will promote awareness and ideas for best practice to increase workforce participation amongst people with a mental illness.

When I talk to large companies about this issue, they say “well how do I get more information?” and “What does best practice look like?”

And we should never overlook small business in all of this.

I know that there are some people whose mental illness prevents them from working.

But it should never exclude them from participating in the community in whatever way they think is best suited to them.

We therefore need a greater focus in all service delivery to assist people to participate meaningfully in the community.

Integration

I talked earlier about the need for service integration. This must address:

- Fragmentation
- Access
- Satisfaction and Appropriateness and
- Coordination

Importantly, proper integration should allow services such as housing and employment to complement and be aligned to, care provided within specific mental health services.

There is widespread recognition that the current overall system is fragmented and that people face multiple barriers to service and system access.

Consumers and carers report significant frustration at having to tell their stories and provide documentation and evidence of past contact with services on multiple occasions.

There is also significant disparity in terms of service system access across Australia.

The further away from a major city that a person lives, the less access they have to General Practitioners and primary health care and a raft of other services.

This matters because more than 80 percent of people, who do seek assistance for mental health related conditions, do so initially via a GP[xvii].

In addition, to the lack of access to GPs, the COAG Reform Council report on access to health services notes that people in rural and remote locations have almost no access to mental health services.

Previous reports have suggested for instance, that 91 percent of psychiatrists have their offices in metropolitan centres[xviii].

On a similar theme, we know that Aboriginal and Torres Strait Islander people often don't have access to primary care.

For Indigenous people, having culturally appropriate services focussing on social and emotional wellbeing is critical for building resilience amongst individuals, families and communities.

Consumer and carer satisfaction with services

In addition to difficulties in accessing services, consumers and carers report low levels of satisfaction with many services.

Of the 35 percent of people experiencing mental illness who did use services, just over half reported that they did not have their needs met by the services that they did use[xix].

This suggests that there is a need for more consumer and carer involvement in the design and delivery of mental health services and a strategy to grow the peer workforce to ensure that services are meeting people's needs.

There is not a successful business in the country that is not acutely aware of the satisfaction of its customers. Why would the mental health system remain blinded to this critical performance data.

Falling through the cracks

Many people simply fall through the cracks of an overly complex system.

Certain groups with complex situations involving substance abuse, post-traumatic stress, intellectual disability and forensic issues or involvement with the child protection system are at high risk for falling through the gaps in fragmented service delivery systems.

People tell me that effective coordination across large and complex systems, such as mental health, housing, employment is just too hard.

I can't accept that. I accept that it is difficult and requires resourcing and time on the part of funding agencies and providers.

But I believe it can work through major cultural change and an adherence to shared values and shared outcomes.

Many large and complex businesses deal with high levels of complexity and disaggregation by promoting a sense of shared values and high levels of trust with very clear accountability structures.

So knowing this why do government continue to fund fragments of services on a piecemeal basis in isolation from each other? And knowing this, why don't service providers do more to build collaborations and partnerships to offer integrated, co-located services.

Some specific ideas for action

So, some specific ideas for action.

We need to pool funding in specific locations and for specific populations to support services that are integrated and built around the individual.

We need organisations working on the ground to enter brave new partnerships to provide co-located and complimentary services in single locations

We need to build systems for sharing data that can support multiple agencies – government and non-government.

We need to think about our models of housing provision, as I said earlier. That is, bring together and housing support in one wrap around model, not five or ten.

Driving a Decade of Reform

As I said, this is by no means a conclusive list of ideas. The Council will be working on advancing this system reform and we want your ideas and suggestions.

I want to conclude by talking about the overall approach to system change.

Firstly, we need long-term certainty of the funding envelope. We can't afford boom and bust times. We need clear triggers for growth as budget circumstances permit. We need to tackle poor performing programs and expand those that give us the best outcomes.

We need a staged approach and start where it matters most.

As we have all heard Pat McGorry say;

- this means programs to turn off the tap by preventing mental illness and intervening early;

and programs to mop up the mess for those who have fallen through the cracks by assisting them to secure better health, stable and supported housing and employment and social participation.

Of course in all reform, nationally agreed performance indicators and targets are essential. We have just been through an extensive process to identify indicators and targets that would make a real difference in people's lives and these should be our starting point.

Critically, we need to take a change management approach that embraces continuous improvement. We need to think about the structures and institutions that can progress this kind of reform.

Stability in the current institutional arrangements will therefore be important.

We must be patient and inclusive and be willing to subject ourselves to a contest of ideas. There will never be one right idea.

We must do everything we can to collaborate not compete if we are to be an effective voice and achieve an effective system.

But the kind of change I am talking about must begin with a change in mind set. What is really needed here is a social movement for a fundamental attitudinal change in our community.

Because wide acceptance, understanding and openness is, in my view, the key, to building the world's best mental health system.

Let me illustrate this and finish with a personal story

My parents were not married. For years I watched my mother experience humiliation, rejection and exclusion from even the most basic services such as social security when my parents separated.

I found out my parents had not married when I was at university. This actually changed my career choice. One of my supervisors suggested I go into the diplomatic corps.

He asked me for my original birth certificate. When I told him about my parents, he said "you won't get in, think of something else."

I never tested it so I don't know whether he was right or wrong, but such was the perception at the time.

I tell this story to highlight the power of social movements, the power of attitudinal change, the power of time and changed values.

I don't think we can imagine those attitudes prevailing today. I can't imagine someone changing their career course based on the marital status of their parents.

Similarly, it is not so long ago that homosexuality was illegal and whilst we have a long way to go on this issue, the power of that social movement for change has removed so much discrimination and stigma for gay and lesbian people.

Whilst I am totally aware that some people experiencing severe mental illness occasionally present severe and challenging behaviours, I am passionately committed to working on that social movement for acceptance and attitudinal change.

Because a good society should never be characterised by how it treats the richest, the smartest, the fittest.

A good society should be judged by how it treats the most vulnerable, how it deals with the ramifications of the poor choices people make and how it treats people with an illness or a disability whose choices are fundamentally constrained by factors which are often beyond their control.

That focus must be about people realising their full potential, about restoring and preserving people's dignity.

That realisation can only come about through the carers and the organisations and the individual workers who work tirelessly in the mental health sector. Many of you are here tonight.

You probably don't get the reward or recognition you deserve, but for what it is worth, I want to place on record tonight my thanks and my commitment to you.

Because I know that, in that moment when things go shockingly wrong for people, when they cannot see their way out of something,

- it is an individual, a carer, an organisation or, in my family's case, the local church,

- that reaches in and pulls that person or family back from the brink and puts them back on track to achieve their goals, whatever they may be.

Whether it is aiming for a job or just getting through the day.

You are the embodiment of a thoughtful, understanding and decent society.

The kind of society we aspire to for ourselves, the kind of society Grace Groom aspired to and the kind of society we should aspire to for future generations.

Thank you.

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