



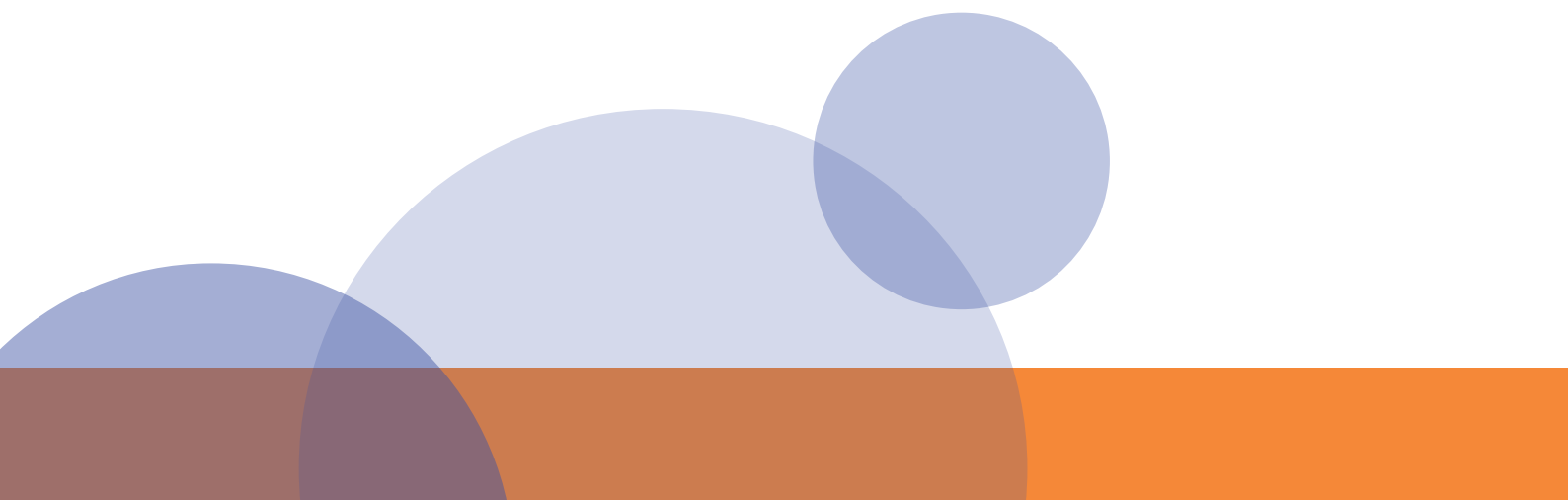
**Mental
Health**
Commission
of New South Wales



Participant discussions from
*Family and Carer Leadership in Mental Health: Why
it matters*

Hosted by
**Mental Health, Alcohol and Drug Directorate,
Department of Health and Human Services,
Tasmania**

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This article includes the discussions and presentations of participants in this event but does not necessarily reflect the views or policies of the Mental Health Commission of NSW.

Family and Carer Leadership in Mental Health: Why It Matters

By Hilary Burden

People who experience mental illness and their family members and carers are playing an increasingly important leadership roles in policy and planning within mental health services. A group of such leaders from North Queensland, WA, Victoria, Tasmania, NSW and County Kildare, Ireland came together in Launceston to share their experiences, challenges and learnings as part of the International Initiative for Mental Health Leadership Exchange hosted by the Mental Health Commission of NSW.

The day starts with the sharing of each other's stories.

It is striking how each person at the table has invaluable life experience of being a carer or 'consumer' - or both. People without direct experience may not realize how close we are, in the everyday, to mental illness. Here, everyone is touched. Is it just this group? Or, is there a degree of inevitability that people who have been mentally unwell, or who have cared for someone in that situation, are more drawn to the caring services?

All of the people in this room are leaders in at least one area of mental health provision, but in considering why family and carer leadership in mental health matters, it helps to look at the personal lives of the people in this room and what has drawn them to becoming passionate advocates for systemic change.

When she was younger, Lynette had experienced suicidal thoughts due to pain, the result of a back injury at work. Many years later she was diagnosed with PTSD from a separate trauma. Lynette has provided ongoing support to two brothers; one of whom has a diagnosis of bipolar and one who lives with an intellectual disability and anxiety.

Rachael, who cares for a child living with autism, spoke of the title of carer "being a barrier to receiving the services I needed".

Maxine was the first single foster parent in Tasmania to foster a disabled person. “As a parent that gave me a whole lot of insights about being in a world where nobody believes you and trying to get your space at a table full of experts.”

Debbie has lived experience as a mental health carer but in the end “had to have some help herself”, switching to a career in television, before returning to the health sector “to make life better for others”.

Sandra’s son developed schizophrenia when he was 19. She says her experience of the mental health system “was so dreadful she felt compelled to do something about it”.

Liam spoke of being diagnosed with OCD and inhibiting depression in his late teens at a time when child mental health services in Ireland didn’t exist. He sees people who are tired of fighting the system, and wants psychiatrists to move away from the paternalistic model of training and recognize explicitly the crucial role of carers.

Malcolm, formerly a principal at a school in one of the poorest areas of Tasmania, learned about being the main carer for his wife (who has OCD) simply by doing it. “You can’t find the places to help,” because you’re too busy or they’re not there. You won’t find the time to access them if no one tells you they are there.”

And Carmel, who experienced psychotic depression as a full time student of social work, and is now a single mother of three, says she nearly didn’t come because her son has schizophrenia and he’s not travelling so well. She knows, “If you don’t have the family, money or a good job, you really are on the outer. You feel isolated from society and think everyone would be much better without you.”

Over the course of the two days, isolation from the system designed to support and understand them became a recurring theme.

“We build huge expectations and barriers and put up walls as professionals,” says Maxine, “but we don’t know how to sit with another person and say ‘I don’t know’ or ‘let’s take this journey together’.” At today’s event, known as a ‘match’, the personal is respected though not indulged. Sandra and Carmel, whose passion and interests lie at the grassroots level of information and

personal experience, are told by their host Lynette that this meeting is about “a systemic approach”:

“When we start talking about our own lived experience we can get bogged down in that,” Lynette explains, “and we don’t meet the needs of this leadership exchange.”

Liam says personal stories are important in so far as they inform improved policy or improved service delivery – “but it’s not that we don’t value or respect those stories.” And Rachael acknowledges, “It’s so rare we get these opportunities to come together and talk about these things at this level. It’s so good to use it in the right way.”

They are only an hour in and yet consideration is already being given to how the group will continue to support and communicate with each other at the end of the match. Jackie shares how the Canadian IIMHL is still active as a group, having formed 10 years ago “before social media”. She points out how the connections have really helped her in her advocacy positions to advocate for better services and to stop people from saying automatically ‘we’re the best in the world [in Australia]’.

The group shares the latest Slack App to facilitate keeping in touch.

Next, a discussion about what everyone means by ‘leadership’. The group agrees it is dependent on first followers, on shared values, on consistently questioning your own motivations, and on allowing people to have a forum where they can make their voices heard. There are tiers of leadership; things leaders are mandated to do.

Accountability emerges a key factor. Leaders must make themselves accountable, “sideways, down, up, all around”. “When we get to a leadership role sometimes we don’t think we’re accountable to anybody,” says Maxine.

Lynette feels there needs to be leadership around implementing policy “that meets the needs of people’s lived experience, how that is translated on the ground, and how it is connected”.

Jackie then challenges the discussion in a way that only a Commissioner with an overall perspective might do: “We can talk about the context of other people to be leaders – accountability, right

space, tiers, communication – but we have a serious issue. That none of us are connected. *None of us.*”

“Clearly we’re all natural leaders or we wouldn’t be here,” she says. “As leaders we all have a vision and purpose and that is what makes us leaders. But peer leadership is about how we connect to each other. How do we take that away from here and, instead of just going back to our jobs, how do we then connect ourselves to others and bring others along?”

Those within the bureaucracy express a frustration at working to values that don’t fit with their position. Pushed to describe those values in three words, Lynette says “inflexible, tedious, removed. In this space, where we’re talking about peer leadership, it doesn’t fit with the bureaucracy. We have experiences and we are peers and we each work in different roles, but what is it about our peer group we need to bring to our organisation? My loyalty is to consumers’ families and carers. And, yes, I have to make it fit...”

Liam is quick to share how every day he has the same experience. “In Ireland I’m employed in the National Health executive,” he says. “It’s very important I do have that voice. But the curious thing is when I’m out and about around the country, they see me with a big ‘HSC’ painted on my back, and it’s as if I’m one of the dark side – even though I represent them.”

Lynette is clearly frustrated by the imposition of being seen as “the government” wherever she goes.

“It’s important we work really hard as leaders in this space to shift that thinking,” she says. “People aren’t their position. My general manager is a human being.”

Throughout this exchange the personal finds ways of emerging through the professional talk. While government leaders are searching for shifts in thinking and ways of promoting and engaging in peer leadership, Carmel brings the conversation back to the reality she deals with every day.

“It’s not all about concepts and ideas,” she says. “It’s about having a space in a building that’s not corporatised, and that someone is willing to open it up for you. It’s about access to Wi-Fi and having information and brochures for carers or mental health patients. Why should it take us 18 months to get a poster on the wall in the hospital to tell people how to ring (carer support

organisation) ARAFMI?”

Lynette is moved to ask Carmel what she needs in terms of leaderships.

“You need a strength-based approach,” suggests Carmel. “You go under it, around it, or you do it for free... and you can’t get precious about qualifications. If you can think outside the square it’s a huge boost. Then you have to have the balls to put it forward and have 15 clinicians think you’re an idiot.”

“What we don’t want is a systemic split from the start where everyone’s listening from a carer’s perspective or a service user’s perspective – there shouldn’t be apartheid,” says Liam, sharing a report called [*Who cares? Listening to the needs and experiences of carers of people with mental illness*](#) prepared by REFOCUS CPsychI and the College of Psychiatrists of Ireland.

“One thing we have in common is that we are all in isolated positions,” says Jackie.

“It’s the nature of advocacy in this country,” says Maxine, who has also acted in leadership roles for COTA and Volunteers Australia.

Lynette, explaining what might seem obvious to people who work in the private sector, says “we shouldn’t need a policy to tell staff about how to be client centred. It’s about having a set of principles and more of a philosophy.”

There is discussion around the need for leaders in a community space to talk about building the capacity of family and friends alongside building the capacity of the service. “The carer needs to be put at clinician level,” says Carmel. But how, when such disconnect is evidenced between the service and its customers?

Overwhelmingly, the day returned to the human stories that started it. “It’s the stories we tell,” says Liam, “particularly those told by people who are stressed by relating with a system. They don’t tell us ‘we attended six times last year’. It’s more, ‘I was treated on one of those six occasions by such and such a therapist...’ They’re almost case studies. If you have those, it lends huge credibility to what you’re trying to do.”

Sandra introduced the match to Beautiful Minds, volunteers who fundraise and advocate to

improve facilities and raise mental health awareness in South Western Sydney which she says has 14 out of 20 of the poorest suburbs in Australia. Harmony House, an acute mental health unit attached to Campbelltown Hospital, was opened in 2008 thanks to their efforts. In 2012, they created the Waratah Recovery Garden for patients at the unit, turning the garden from a dustbowl to one nurturing health and recovery. Now they are fundraising to create an outdoor activity space at Birunji, a 20-bed youth acute mental health unit also attached to Campbelltown Hospital.

“Acute mental health places are forgotten places,” says Sandra. “There is no fundraising for these units. Hospitals have auxiliaries. Art galleries have friends. Schools have P&Fs. Acute mental health facilities have no one. We are fostering peace, beauty and exercise while they are experiencing the worst moments of their lives.” She adds that traditionally the Birunji people used waratah for depression. So, Beautiful Minds volunteers are selling waratahs to raise funds for the acute youth unit. It’s estimated their work equates to about 25,000 hours each year, in dollar terms, about \$500,000.

Support by carers has a way of continuing in spite of either a lack of funds or the frustrations associated with the slow pace of services. Does the bureaucracy take this for granted? If so, at what cost?

The challenge for leaders expressed at the Launceston match is to find better ways to connect with a community’s mental health needs, for the bureaucracy to operate more like a community that cares.

“Sometimes people get caught up in what’s professional,” says Carmel, “but sometimes there are things that need to be done that don’t require the professional face.”

Debbie introduces [*A Practical Guide for Working With Carers of People With a Mental Illness \(2016\)*](#), which she helped develop as CEO of Helping Minds. This work, she says, isn’t coming through staff but through an NGO. “Staff are so focused on their patient and haven’t had the introduction or experience in working with carers or family. They haven’t realised the benefits. They might like to, but they’re so time poor.”

While Jackie says The National Standards for Mental Health Services 2010 is the gold standard, it is “Debbie’s Practical Guide” the group embraces because it looks more like action than a policy that

checks that people are doing their job. “This is a guide that we can follow,” says Malcolm. Liam agrees: “We’re putting this together at home. It’s made this 12,000 mile trip worthwhile.” Based on the UK model (consumer, carer, psychiatrist), Debbie explains it took a steering group of five, engaging stakeholders from every part of the mental health spectrum, sitting around a large table in face-to-face meetings. Ideally, she would like these standards to be picked up as part of a mental health accreditation process. While Malcolm asks what’s being done that’s not being done now, Jackie explains there are both national mental health and NGO standards.

“It’s a little bit ad hoc for me,” she says. “They’ve never been implemented across the board.”

Lynette wonders with so many standards “how do we incorporate them?”.

Maxine asks “could the Helping Minds guide be the way to do it?”

“If we’re piloting something it should be piloted with the involvement of NGOs,” says Rachael. “It’s really useful when combining work with community and clinical work, where there are often very clear tensions. This document should almost be a targeted guide for when we do combined work.”

Jackie sees her role as talking about this at a national level, to start making people aware of it, and of its importance. “It’s important the trials are done first so we have some research to show that it works.”

Rachael points out that “the politics and competitive nature of the sector stops really good guides being implemented when it’s associated with other service providers – and I don’t know how we get around that.”

Debbie says as CEO of Helping Minds “it doesn’t matter who we partner with. We should be partnering with everybody to make sure the message gets through”.

A range of solutions to the key challenges are taken away from the Launceston match:

- ‘Area leads’ with carers coming given formal structured roles within services;
- Paid participation, “because how can we lift up carers if they are not valued?”;
- Mental health inter-agency meetings with all stakeholders at the table;
- Swapping business cards;

- Developing a carer engagement framework.

For Liam, communication has to be two-way. “We want to be absolutely insistent on a two way dialogue. The days of ‘we tell you our stories and share our experiences and we put them to you and then we hear nothing’ – that model has to completely change.”

Sandra adds, “We must role-model that change. If we’re not prepared to find the evidence, then we’re not being true or authentic in what we’re asking other people to do.”

But the feeling expressed at the close by Carmel is endorsed around the table. “I can read lots of strategies, emails, updates newsletters... but coming together like this in real time with real people is so valuable,” she says. “Being in the company of people with shared vision and passion about what we’re doing. It’s almost impossible to put somebody in the shoes of a carer who hasn’t been there.”

“Locks on toilet doors” became a metaphor at the match for the inability of the system to respond quickly to carer or consumer needs. (Thanks to carers making it an issue, locks were put on toilet doors in mental health facilities where two of the match leaders had been involved).

“It’s the stories that have the impact,” reinforces Liam. “It’s recognition of human dignity that you can go to the toilet and lock the door.”

Jackie presses the group to show how effective and efficient their service is. While some around the table mention a suite of evidence, Sandra knows how many flowers she sells: “We talked to 5000 people about mental illness – each time a volunteer sold a waratah.”

“A leader is best when people barely know he exists, when his work is done, his aim fulfilled, they will say: we did it ourselves.” Lao Tzu

This quote, shared by Liam, ‘went viral’ in the Launceston match.