ACKNOWLEDGMENT + CREATION OF *a Central Role for People with Lived Experience*

People with

SEVERE, ENDURING ME PSYCHOSOCIAL DISABI

The mental health system urgently needs to redirect its attention to whole-of-life needs and not just medication and crisis-driven service delivery.

DESPITE YEARS OF NATIONAL AND STATE MENTAL HEALTH REFORMS ACROSS AUSTRALIA, MANY INDIVIDUALS WHO EXPERIENCE PSYCHOSOCIAL DISABILITIES AS A CONSEQUENCE OF SEVERE AND ENDURING MENTAL ILLNESS STILL DO NOT RECEIVE THE SUPPORTS THEY SO DESPERATELY NEED. THIS OFTEN RESULTS IN TRAGIC CONSEQUENCES, INCLUDING A HIGH PROPORTION OF THOSE WITH A SEVERE MENTAL ILLNESS BECOMING HOMELESS OR INCARCERATED FOR MINOR CRIMES, AND WORSE.

There is a dearth of research from among this cohort. Their number has been estimated to be anywhere between 60,000 and 200,000. What we do know is that they are among the most socially and medically marginalised members of the Australian community.

We also know that, despite the fact that many who have a psychosocial disability are monitored and treated by qualified health professionals for their mental health problems, their physical health issues are often not addressed (see Janet Meagher's article). According to the World Health Organization and SANE Australia, the average life expectancy of people with schizophrenia, for example, is at least 25 years less than that of the general population.

This appalling situation is substantiated in many recent reports, including the report card presented to the Prime Minister by the National Mental Health Commission in September 2012.

Seventy eight percent of persons living with a mental illness are still living with their families because housing options are so limited. Across Australia, there are very few good examples of supported accommodation. Often, the only alternative is living in privately-owned, substandard facilities. Family carers have serious concerns about the lack of appropriately supported accommodation and what will happen to their loved ones when they are no longer around to support them, and the reports reveal that this is impacting significantly on the health and wellbeing of family and friends, as evidenced in recent reports.

Family mental health carers across Australia are repeatedly reporting that support agencies refuse to assist their loved ones, who are expected to have 'goals', to 'lead their own recovery' and to 'drive their own care and support', leaving carers at a loss as to how they fit into 'care'.

National Mental Health Consumer and Carer Forum

The National Mental Health Consumer and Carer Forum (NMHCCF) was developed collaboratively in 2002 by peak consumer and carer groups and the Australian Health Ministers' Advisory Council. The NMHCCF is the combined, national voice for mental health consumers and carers participating in the development of mental health policy and sector development in Australia. Our membership includes one representative consumer and one representative carer from each Australian state and territory and representatives from six national health consumer and carer organisations. The Forum aims to improve the wellbeing and quality of life of mental health consumers and carers throughout Australia

NTAL ILLNESS, LITIES & THEIR CARERS

by the National Mental Health Consumer and Carer Forum

The National Mental Health Consumer and Carer Forum is the combined, national voice for mental health consumers and carers participating in the development of mental health policy and sector development in Australia.

through promoting their rights; creating a responsive, recovery-focused service system; and through supporting innovation in service delivery appropriate to different life stages.

To do this the Forum:

- Provides a strong, united voice for mental health consumers and carers focused on influencing national, state and territory policy and discussion about service development.
- Draws on our members' lived experience and expertise in mental health to identify what does and does not work in mental health, as well as key human service policies and practice.
- Promotes approaches that support individual recovery and contribute to an improved mental health and human services system at all levels.

The NMHCCF members use their lived experience, understandings of the mental health system and communications skills in systemic advocacy to promote the issues and concerns of Australian mental health consumers and carers. NMHCCF members represent consumers and carers on national and state committees including working groups, expert reference groups, forums and summits. The NMHCCF provides a tangible opportunity for mental health consumers and carers to play a positive role in reforming the mental health sector to improve the lives of millions of Australians.

The NMHCCF has six priority work areas:

- National mental health reforms.
- Psychosocial disability issues and disability sector linkages.
- Workforce development and education.
- Forum partnerships and alliances.
- Accountability and promotion.
- Consumer and carer research.

We produce submissions, advocacy briefs and position statements on issues that are important to consumers and carers, including seclusion and restraint, peer workforce, stigma, confidentiality and psychosocial disability. Focusing on the latter, the NMHCCF publication, Unravelling Psychosocial Disability, outlines our position on this controversial issue that is rarely discussed openly.

To identify individual needs and look clearly at how everyone with severe and enduring mental illness and psychosocial disabilities can make their way in the world, it is critical that there is a comprehensive assessment of an individual's functional capacity by people who well understand mental illness and psychosocial disabilities and have the high-level skills to conduct appropriate assessments. Families and carers must be included in this assessment, where appropriate to do so, particularly when the individual experiences anosognosia, a condition which affects approximately 60% of those with schizophrenia. Having this condition means that they are unaware that they have an illness, and this impacts significantly on their capacity to lead their own recovery.

It is essential that governments take the lead in providing policy - and direction - and adequate funding for the wide range of supported accommodation options that are needed by persons with psychosocial disabilities in order to make a positive difference to their lives and that of carers. People with psychosocial disabilities, like anyone else in our community, are entitled to the full rights of citizenship and this means that they have a right to safe and adequate housing, and a right to be adequately supported to achieve the highest level of function they possibly can.

Anyone unable to live independently requires appropriately supported accommodation where they can be properly cared for, where their physical and mental health is properly monitored, and they receive decent meals and assistance with their physical and mental health needs and everyday activities. Worldwide research indicates very strongly that there are huge economic gains for the community when its members are adequately supported in this way.

The mental health system urgently needs to redirect its attention to whole-of-life needs and not just medication and crisis-driven service delivery.

We force people into hospital, transported by police, force them to take huge amounts of antipsychotic medications against their will, ignore their physical health and take away control of their money. We cannot continue to do these inhuman and discriminatory things and yet, at the same time, fail to provide the support that aims to help them to live a decent life and become contributing members of society — something everyone wants and deserves whether they have a mental illness or not.

Australia is working on ways to restore varying degrees of health, wellbeing and dignity to the lives of its citizens, including those who have physical disabilities. We need to do the same for those with psychosocial disabilities.

……

To identify individual needs and look clearly at how everyone with severe and enduring mental illness and psychosocial disabilities can make their way in the world, it is critical that there is a comprehensive assessment of an individual's functional capacity by people who well understand mental illness and psychosocial disabilities and have the high-level skills to conduct appropriate assessments.

……

SUPPORTING A CENTRAL ROLE

FOR CARERS & FAMILIES

by Jane Henty

Executive Officer, Mental Health Carers Arafmi Australia

The Health Council of Australia's 2012 Mental Health Carers Report: Recognition and Respect was an insight into the lives of some of the most dedicated yet vulnerable members of our community, namely mental health carers. In this article, the term carer refers to people who provide unpaid, practical and emotional support to a person with mental health issues, such as relatives, partners, friends or neighbours. A carer may or may not live with the person they support and they do have to be identified by the individual with mental health issues to be their carer (Clements: 1996).

Carers provide help, understanding, guidance, support and a financial safety net for people with a mental illness. This can take its toll financially, emotionally and phsycially. As a carer in the report says, 'The support services provide all the contact details to the consumer, but who can the carer call when they are worried and afraid? The concern that when your child goes away they may not come back, or nights when you lay awake with worry that they might not be alive the next morning.'

It is critical that we listen to, and document, the views and experiences of carers.

> I GENERALLY HEARD SIMILAR COMMENTS FROM FAMILIES: HOW CAN THIS HAVE HAPPENED, COULD I HAVE PREVENTED IT, WHAT CAN I DO?

Shift in emphasis

Asylums have been closed for 30 years. Subsequently the emphasis of mental healthcare has shifted to home-based and community care, with families and carers taking increased responsibility in caring roles, often with minimal support from communities or services. This can lead to carers feeling (and being) swamped in a pattern of day-to-day survival, with little hope for the future.

Supporting someone with a mental illness has a negative impact on the health and wellbeing of carers. In 2007, carers were found to have the lowest wellbeing of any large group recorded by the Australian Unity Wellbeing Index (Cummins and Hughes: 2007). The National Mental Health Carer and Consumer Forum in 2011 linked poor carer wellbeing to: the episodic nature of mental illness; the behaviours that can be associated with mental illness; the lack of community recovery-based services and supports for people with mental illness; and lack of appropriate accommodation for people with a mental illness.

Advocates have therefore been calling for improved community support for family members caring for their loved ones with a mental illness. It is crucial that carers receive knowledge and moral and peer support. A carer has emphasised the importance of carer support: 'Mental illness was completely new to me and I had to learn as much as I could whilst (sic) dealing with my sick son. Education and support was provided at a time of despair and bewilderment' (ARAFEMI: 2007).

However, there is still inadequate support for carers. Sharing my professional journey illustrates some of the typical barriers and shifts across the sector.

My experience

Commencing as a graduate psychiatric nurse in 2005 in a Melbourne hospital, I completed four rotations in the acute psychiatric wards, which was a comprehensive crash course in psychiatric nursing. The psychiatric wards were always full. There were always patient admissions, patient discharges and forms to fill out.

Families entered and left the wards at the periphery of our vision. As a nurse, the focus was on a timetable of medications, meals and risk assessments, which would be periodically interrupted by difficult situations, such as a patient absconding or creating a disturbance.

As a nurse, I was sympathetic and concerned for families' needs. However, timetables and processes sometimes got in the way. I think back to how a mother looked at me in concern when I told her she could take her son on leave from the ward. Possibly her concern related to the nature of the illness, or the treatment had not been explained to her, or she was worried that something may happen while he was in her care. However, she could not say anything in front of her son and I did not intervene. His leave papers were signed by the head psychiatrist, so he left. A more family-inclusive approach to the leave arrangements would have supported the mother in her caring role. At the time, the ward culture and work expectations made family inclusion challenging.

Part of the barrier that is often cited within workplaces is whether carer and family involvement in consumers' care and treatment is core business. Since the introduction of the National Standards for Mental Health Services in 1996, it is required to involve consumers and carers in mental health treatment. This imperative has arisen from clear evidence that families, carers and friends are the largest providers of care for people living with mental illness in Australia and that inclusion in care and treatment leads to greater health outcomes for consumers (Falloon: 1998). However, families have often continued to be marginalised and excluded from participating in their loved ones' care (Lakeman: 2008, 203-11). This is concerning given that 'fifty to ninety per cent of the chronically mentally ill live with their relatives following acute psychiatric treatment' (Lauber et al: 2003, 285–289).

After a couple of years of nursing I turned my attention to mental health community rehabilitation and recovery. I wanted to work in the community where recovery from mental illness was the focus of care. I started working for ARAFEMI Victoria as an outreach worker. In this program, families were more central to the consumer's care. I entered into families' private lives, learnt about their hopes and fears, and heard their stories of coming to terms with their loved one having a mental illness. I generally heard similar comments from families: how can this have happened, could I have prevented it, what can I do?

Physical and emotional exhaustion, chronic stress, depression and grief are not unusual among family members. Social isolation and low self-esteem, economic losses, decreased life opportunities, and difficulties accessing effective treatment and support services add to the pressures that carers and families face. The lack of support and information about the illness, management and services compounds these feelings of powerlessness and frustration.

National representation

A deepening respect and commitment for families and carers has led to my role as Executive Officer of Mental Health Carers Arafmi Australia. This organisation represents at national level the interests of the needs and concerns of its members and constituency – families and others voluntarily caring for people with mental illness.

Attending a Carers Conference held in Perth in 2012, I heard the ABC sports presenter and broadcaster, Karen Tighe, share her story about being a carer. She had cared for her husband, Glenn Mitchell, also a sports broadcaster, during his depressive illness. The pain, stress, anxiety and stigma she described brought the audience to tears. I began to really understand how isolating and painful being a carer can be and that often carers are crying out for help, with no-one listening.

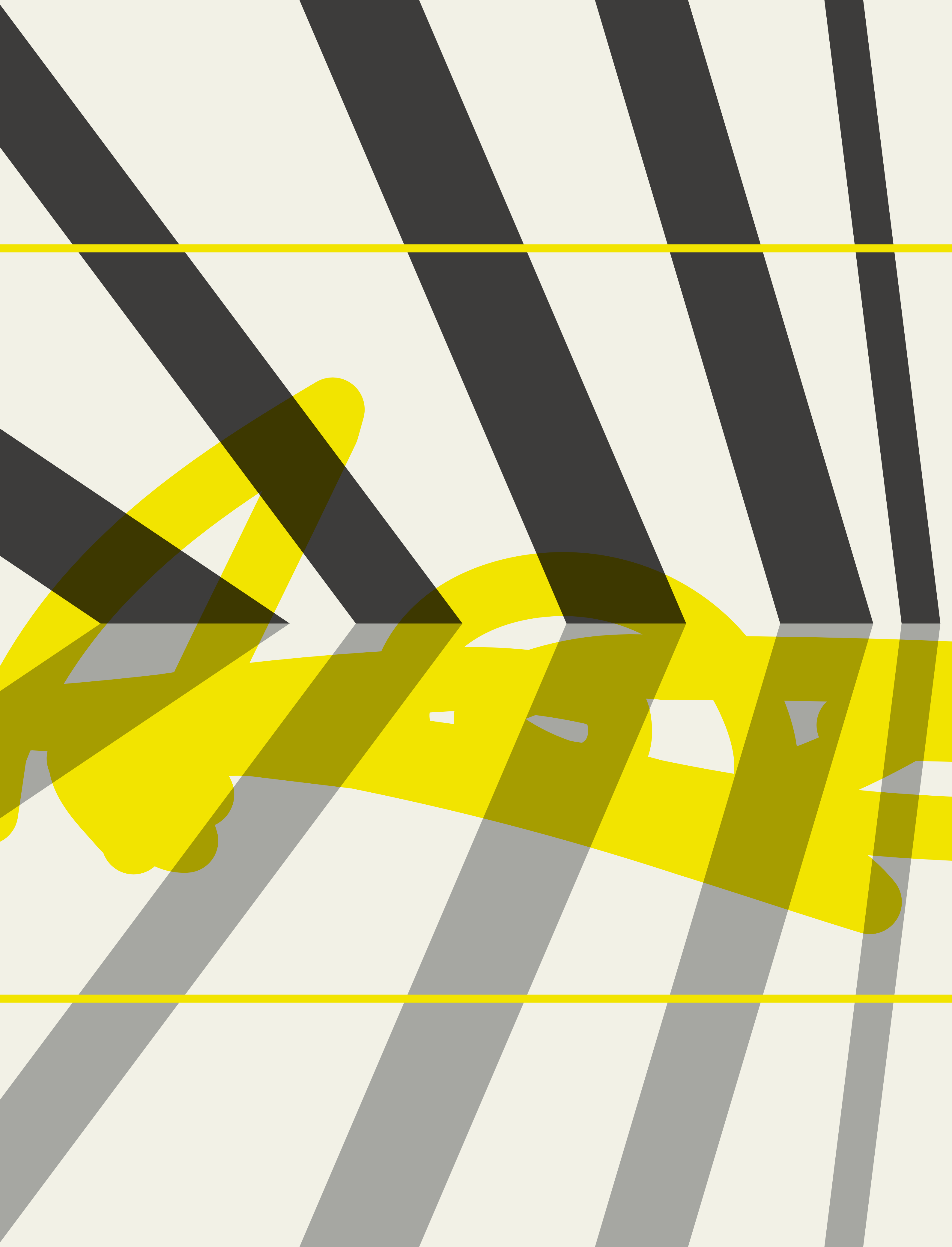
We can decide as a country that we are going to ignore the needs of carers such as Karen, and continue to focus on diverting most government revenue into acute psychiatric beds. The majority of national mental health expenditure in 2010-11 went to public hospital services for admitted consumers, at $1.8 billion, followed by community mental healthcare services at $1.6 billion (AIHW: 2012).

Or we can choose to lead the world in mental health treatment and support by:

- Connecting and empowering families and the community to be involved in psychiatric services and care.
- Reaching out to other sectors, such as housing and education.
- Improving access to carer services and information for carers and family members.
- Integrating services.

And most importantly, we need to give carers hope. We can do this by using personal experience through peer support, and building carers' skills though information, education and support. A focus on empowerment, hope and self-determination is central to recovery from mental illness for both consumers and carers.

The choice is with the policy makers, the government, individual services and the community. So Australia, what are we going to do?



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