



Peak body representing
the community-based
mental health sector in WA

Productivity Commission Inquiry Long Term Care and Support Scheme.

Organisation:

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ABOUT WAAMH.

The Western Australian Association for Mental Health (WAAMH) is the peak mental health representative body in Western Australia for non-government not-for-profit agencies that operate for the benefit of people affected by mental illness.

WAAMH's role

Support the development of the community-based mental health sector, provide systemic advocacy and representation and influence public opinion for the benefit of people with mental illness and their carers.

WAAMH's vision is that:

Western Australian community organizations will lead the way in supporting and including people with mental illness and their carers and providing well governed innovative community-based services focused on recovery.

WAAMH works towards a future in which the health and well-being of people affected by mental illness is promoted and supported by a range of community based mental health services and in which there is community acceptance of people with mental illness. WAAMH supports and encourages the development of the non-government not-for-profit mental health sector.

This submission seeks to:

- Provide our views about the values and principles necessary in making changes to Disability Care and Support in Australia and;
- Express our view of the fundamental place of mental health within the context of disability care and support reform

We cannot answer all of the questions posed by the Issues Paper, but we can identify key values and principles of a reformed system, identify mechanisms that are working currently and provide insight as to how the system could be changed.

Values and Principles: The provision of Disability Care and Support should be underpinned by values and principles. At the core of this support is the principle that the person being supported has the right to be in control of their life. This means that people have a right to:

- Make choices and decisions for themselves;
- Grow and develop in their relationships;
- Be present and participate in the community;
- Have valued roles and contribute; and
- Develop their talents, interests and abilities

These rights are consistent with the United Nations Convention on the Rights of Persons with Disabilities. National reform of Disability Care and Support needs to promote and create actions consistent with this convention. Other values and principles of Disability Care and Support include:

- ✚ Person Centred Support: Support should be built with the **person with disability at the centre** of support planning. People themselves are the experts in their own lives. Thinking of the person with disability as the centre of a 'bullseye', circles of support should be designed with the person in the centre in control. It is important, therefore, for any system built to begin from the perspective that the person with disability is in the centre of that support and in control of their own plan. Often, the person with disability has a primary carer. Their needs and dreams should also be considered and the person with disability and their carer (often a family member) should not be artificially separated.
- ✚ Flexibility and Creativity of Support Options: Because every individual is unique, and one plan does not fit every person, Disability Care and Support should be reformed to support **flexibility around different solutions** that could be created. There should be an incentive for **creativity and sustainability** without disadvantaging people by decreasing their funding allocation substantially. Support should be responsive to the changing circumstances of the individual whether these are improvements or an increased level of support need. Support should be as individual and flexible as the person themselves. This requires agility on the part of a larger framework and at the organisational level.

- ✚ Equitability: Disability Care and Support should be equitable, providing each according to their own needs, choice and preferences. No one should be worse off or unfairly worse off than in the current system.
- ✚ Community Inclusion: No person is an island and the contribution and citizenship of people with a disability should be recognised in their community. The reality is that disability is a community issue, affecting the whole community; therefore, the whole community should contribute to the solution.

Things to Keep

Western Australia is fortunate in many ways to be on the forefront of support to people with a disability, with a functional Disability Services Commission and local support through Local Area Coordination (LAC). The importance of supporting people with disability in Western Australia is bipartisan, sitting firmly in the agenda of government, whatever their political philosophy. We see that there are parts of the existing system which should be retained when considering reform. These include:

- ✚ Individualised service at a local level, such as LAC.
- ✚ Using existing mechanisms
- ✚ Retaining existing services and structures which meet the values and principles of a reformed system of the provision of Disability Care and Support.
- ✚ Supporting broader social interventions ongoing such as access improvement and universal design.

Things to Change

We strongly support a need for a change in Disability Care and Support and have identified a number of areas in which we believe change should occur under reform.

- ✚ Mental health should be 'in': Mental health should be in the scope of the Disability Care and Support reform. People with mental illness have a disability as such and this disability should be recognised along with physical or intellectual disability. Like people who are challenged by other disabilities, people with mental illness can contribute and have right of citizenship. Putting mental health into the Disability Care and Support discussion will potentially allow funding to be allocated to assist people with mental illness on their recovery journey and can promote inclusion into communities and decrease of stigma.
- ✚ Disability Care and Support should be viewed from a strengths based perspective rather than a deficit based perspective: People with disability are employees, consumers and contributing members to society. Their disability is a part of who they are, but not a definition of their capacity and heart. Reform of systems should begin from the perspective that people with disability have something to offer the community of real value- that there is reciprocity in our relationships and not a sense of people with disability only receiving benefit, but putting into relationships and community.

- ✚ The perception that people with disabilities can't and don't work needs to change: People with disabilities can and do work. They are valuable contributing members of the community. People with disabilities should be afforded the opportunity to participate in work and have an incentive for doing so. Their quantum of support and funding should not be unfairly disadvantaged by taking up paid employment.
- ✚ Contribution does not equal productivity: People with disability can make a contribution and be productive, regardless of whether or not they are in paid employment. People's contribution to the community in which they belong is productive, and enhances the community itself. Everyone can learn, everyone can communicate, even without words and the community can benefit.
- ✚ Disability is not the property of the person: Disability is not the property or issue for a single individual. It has a societal aspect. Not only is the person with disability affected by their circumstance, but their fathers, mothers, siblings, co-workers and larger community is impacted. Both people with disability and people who love and care for them affect their community by what they can and can't access, by what they choose to purchase, by events they choose to attend, by schools they attend and by services they support. Disability is not an individual issue, but one for the whole community.
- ✚ Provision of Disability Care and Support should be equitable: The allocation of support for people should be equitable across similar needs/circumstances.
- ✚ Systemic shuffling should be eliminated: There is a clear relationship between people with disability and other significant areas namely Health, Mental Health and Ageing. These areas should not continue to operate in silos, decreasing productivity across the system and increasing the confusion for people with disability. People with disability also age, and people who age have acquired disability. People who age and/or have disability can have mental health issues either related, or not, to their individual circumstance. People should be able to access support across any of these areas with a minimum of confusion and anxiety. Passing the buck between ageing, disability, mental health and health is not going to assist the government in achieving its overarching policy goal to enhance the quality of life and increase the economic and social participation of people with disability and their families, including enhancing and protecting their rights.

Mental health has a fundamental place within the context of disability care and support reform

The prevalence of mental illness is high in Australia and other western countries. About one in five adults will experience symptoms of mental illness in a 12 month period - this means that 2.4 million Australians had at least one condition during the last year. The most prevalent mental health problems are anxiety-related and depressive disorders. Approximately ten per cent of the population is affected by an anxiety-related disorder in any one year, and six per cent of the population

experience depressive disorders in a year.¹ Psychotic illnesses such as schizophrenia and severe mood disorders are less common, but are usually very disabling. Yet only one third of sufferers receive help from health services – a staggering 65 percent of sufferers battle their disorder alone or only with the help of family.² Mental illness afflicts more Australians than almost all other health disorders. Only cancer and heart disease impact more people.

Mental illness has become the largest cause of disability in Australia. With mental health disability affecting an estimated 25% of people with disability needing constant or frequent support³ it's time to include the care and support of people with mental illness in the conversation about reform.

The employment participation rate of people with a diagnosed mental illness which warrants Disability Support Pension is lower than for other disability groups. Illnesses such as Schizophrenia and others incorporating psychosis tend to affect people in their youth leading to years of lost productivity and quality of life. People with mental illnesses are also over-represented in the justice system. With the right sort of assistance recovery is possible; however the assistance currently available is failing many of these young people. They are more likely to suffer from stigma than many other groups, often because of the way in which they are commonly represented in the media and in film and popular culture.

There is a gap between the kinds of support services offered by mobile, psychosocial case management models which support recovery and crisis intervention and the leap forward into employment services, where the expectation is that the recovery will be nurtured in the workplace. In reality, work can be stressful and demanding, and the idea that entry-level work is less stressful and demanding than skilled work is possibly a stereotype. Often entry-level work is demanding in terms of negotiating the social milieu, and demanding in terms of productivity required, and demanding in terms of understanding and tolerance of supervisors. Entry level jobs often start earlier than other jobs and are often more physically demanding. If they are boring, they require a high level of concentration to maintain productivity.

Although people with mental illness can benefit from work, we also need to understand what is at stake and what might be lost. One thing is the space to retreat from the demands of the world, and from the situations that increase anxiety and trigger relapse. While people with mental illness are often more motivated than many others to go to work as it offers some sense of normality and pride, they are also pulled away from going through fear of not measuring up. Because of the nature of the disability this can often be greater than for other groups (depending upon the diagnosis), so an easing back into the community is often needed. Ideally psychological monitoring and assistance should also be made available for graduated return to work and support. The current funding system for Disability

¹ National Survey of Mental Health and Wellbeing 2009

² Mental Health Council of Australia. (2010). *Mental Health Fact Sheet*. Retrieved from: <http://www.mhca.org.au/documents/AboutMentalHealth/FactsonMentalHealth.pdf>

³ DIG (2009b), Productivity Commission Issues Paper Disability Care and Support Figure 1

Employment Support does not necessarily support return to work for people with mental illnesses as well as it does for people with other conditions.

What needs to be created? More opportunities for learning and practicing work skills in a supportive environment. More opportunities for developing skills that are valued and thus help to overcome any stigma associated with the diagnosis. More government vacancies that are made available to people with a diagnosed mental illness. More specifically targeted groups to learn skills for managing stress in the workplace, and more leadership and commitment by government in creating government departments as both productive and mentally healthy places for employees, and for such departments to act as exemplars for private industry.

People with mental illness continue to experience significant discrimination and stigma associated with their illness. WAAMH continues our journey to see people we support and their families:

- welcomed by communities who embrace differences and recognise gifts, attributions and strengths before illness, deficits and dysfunction;
- move from isolation and vulnerability to be able to access a range of formal and informal supports

People with an intellectual disability and mental illness (dual diagnosis) often have complex and high support needs and are in need of improved access to a broad range of supports.

There is some relationship between the nature and the extent of disability, to the frequency of need for assistance with core activities. "People with intellectual disability were the most likely to need assistance six or more times a day."⁴The effect of caring for a person with intellectual disability on the carers' physical and mental health is well documented.

Two per cent of the Australian population have an intellectual disability and the prevalence of mental illness in this population is 30-50 per cent, the equivalent of at least 100,000 people. Their needs are often ignored because they fall between the gaps. Often the two disorders are treated separately or people are only referred onto a specialist service when a holistic approach to a person's recovery is taken.

In practice we have found it challenging to provide support to people with significant mental illness and an intellectual disability. In this example, from Perth Home Care Services, a WAAMH member, a woman called Maria continues to reside in Graylands hospital and has done so for the 3 years they have been funded to support her. The issues surrounding her transition to the community are complex. Despite the challenges they have some 'good news' stories to tell about their journey in supporting people with complex mental illness and disabilities. Sarah's story is indicated below:

⁴ Disability and its Relationship to Health Conditions and other Factors AIHW 2004



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Janice (mother) cares for Sarah (daughter with mental illness and disabilities). When RHCS met Janice she was felt depressed and had difficulty coping with Sarah's challenging behaviours, the withdrawal of support by a service provider in Regional WA over OSH concerns, and rejection of an application for funded assistance. A relationship of trust was established by RHCS with Sarah to support development of goals and facilitate progress towards achievement. Sarah now has a more positive approach, has membership at a local gym and Janice is also attending (supported by CCRC). Both mum and daughter also attend the local pool daily for 30-45 minutes. Through the BIG Plan sessions, Janice was able to identify her gifts and talents and now is starting her own business from home with the support and partnership of her daughter. RHCS has assisted Janice with funding applications and recently approval was received for up to 20 hours a week respite and ATE funding for Sarah. at home with the support and partnership of her daughter. RHCS has assisted Janice with funding applications and recently approval was received for up to 20 hours a week respite and ATE funding for Sarah.

For people with dual diagnosis as well as for every person with a mental illness, and hopes for recovery, mental illness should be part of the disability care and support discussion.