Senate Community Affairs
Legislation Committee inquiry
into the National Disability
Insurance Scheme
Amendment (Quality and
Safeguards Commission and
Other Measures) Bill 2017



For inquiries please contact

Debbie Childs

HelpingMinds provides a range of supports to families and individuals experiencing issues arising from mental distress. We work directly with family members and friends in an ongoing caring role and with individuals who require support as a result of a mental health issue or psychosocial disability.

This submission is based on the experiences of individuals and family members and friends in a caring role who have shared their experiences with us. Our sincere thanks to those people for sharing their lived experience. This is invaluable evidence necessary for the improvement of service delivery.

Over 72,000 people in Western Australia have identified as requiring assistance due to a psychological condition. The vast majority of people who need assistance receive it from their family and friends who provide support in cognitive and emotional tasks, personal and health care, mobility, household tasks, transport, and reading and writing tasks¹.

The number of family members and friends in Western Australia providing care to a person with a need for assistance due to a psychological condition has been estimated at around 61,000².

However, academic researchers suggest that this figure is a considerable underestimate and that approximately 15 per cent of all Australian adults are providing care and support to a family member or friend with disability related to mental ill health³. Many young people, including children, are also in an ongoing caring role for their parents and other family members living with psychosocial disability.

The lives of people with mental health issues and their family members and friends who support them can become closely entwined. HelpingMinds encourages a 'family centred' approach to service delivery⁴. This evidence-based approach positions the individual at the centre of their support network and acknowledges that people in the support network are likely to need information and support themselves. By providing psycho education, communication and coping skills, and information about services and rights, better outcomes can be achieved for individuals and for the family members or friends who

¹ Australian Bureau of Statistics. 2015. Survey of Disability, Ageing and Carers: Psychological Disability, 2012 – Australia. Tables 3 and 8.

² Australian Bureau of Statistics. 2014. Caring in the Community, Australia, 2012. Table 14.

³ Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T. and Johnston, A. 2010. 'Who cares? A profile of people who care for relatives with a mental disorder'. *Australian and New Zealand Journal of Psychiatry*, 44:929-937.

⁴ COPMI. 2016. 'Family recovery'. Gateway to Evidence that Matters, Edition 23.

provide ongoing support and who may require support themselves to continue this role in a positive manner⁵.

As an organisation that both delivers NDIS services and provides services to family members and friends in a caring role, we would like to raise a few questions for consideration.

- 1. How will the registration requirements impact on the provision of NDIS services by family members to the NDIS participant?
- 2. Will the additional registration requirements impact on the extent to which participants can choose their provider?
- 3. What provisions exist that allow family members and friends in a caring role to make a complaint about their treatment by a service provider? In WA, legislation exists that provides for complaints to be made by carers about their treatment as carers. The Carers Recognition Act 2004 recognises that carers make an important contribution to the lives of the people they support, and if their views are not taken into consideration, this limits the ability of the family member/friend to sustain the caring role. In WA, carers can make a complaint to the Health and Disability Services Complaints Office regarding any disability organisation funded through the Disability Services Commission with the goal of achieving better outcomes for the individual and their family but also to achieve improvements in quality at the individual service provider level and the systemic level. Are there any provisions for this in the national model?
- 4. What community support will be funded to be available to assist individual participants or their family member/friend/nominee to make a complaint? Our individual advocacy service frequently assists people to make complaints about service provision because the individual is so distressed, or time poor, or lacking confidence and information, or the complaints process is so onerous, that they feel unable to make the complaint without support.

⁵ National Institute for Health and Care Excellence. 2014. *Psychosis and schizophrenia in adults: Prevention and management.* National Institute for Health and Care Excellence