



6 April 2016

Committee Secretary
Senate Standing Committees on Community Affairs
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Parliament House
Canberra ACT 2600
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Senate Standing Committees on Community Affairs inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia

Dear Sir/Madam,

Carers NSW welcomes the opportunity to provide a submission to the Senate Standing Committees on Community Affairs inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia. Carers NSW is an organisation for people who provide informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness, or who is frail.

Carers NSW supports and advocates for carers in NSW and is the only state-wide organisation that has all carers as its primary focus. Carers NSW is also part of the National Network of Carers Associations, which works collaboratively to lead change and action for carers. Carers NSW vision is for an Australia that values and supports all carers, and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community, and government.

Our submission focuses on the needs and experiences of carers impacted by the indefinite detention of the person they care for. It draws on unpublished research conducted by Carers NSW regarding the experiences of carers of people with a mental illness who are in prison. The terms of reference most relevant to carers are addressed chronologically below.

b. the experiences of individuals with cognitive and psychiatric impairment who are imprisoned or detained indefinitely

Carers NSW would first like to express our disappointment that carers are not included in the terms of reference for this inquiry. Not all people with a cognitive or psychiatric impairment have, or identify as having a carer, however many do. For example, according to the 2012 Survey of Disability, Ageing and Carers, around half of the people with disability in NSW who needed assistance with cognitive or emotional tasks received support from an informal carer.¹

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A carer's role does not end when the person they care moves to an institutional environment. Rather, the move to an institutional environment such as prison simply changes the nature of the caring role and can result in increased demands on the carer, especially if significant effort is involved in contacting or visiting the person. For example, the lack of forensic facilities for young people in NSW means that carers often have to travel long distances and stay overnight to see their loved one.² Navigating the justice system and getting timely information about the person they care for can also be incredibly taxing for carers.

Regardless of the residential situation of the care recipient, carers often retain significant caring responsibilities. This can include financial support and management, assistance with decision making, provision of information, emotional and social support and support with communication needs. Additionally carers retain the stress and anxiety that can be associated with caring for someone with a cognitive or psychiatric impairment, and anxiety about how their loved one will manage within the justice system.

Carers can experience additional strain due to the stigma and trauma associated with a person's detention and engagement with the justice system.³ Uncertainty and fear about how the person's care needs will be met in detention may be a cause of major concern, especially if they have previously provided intensive support in the home or community. At the same time, institutionalisation can make the carer less visible, isolating them from available support and locking them out of decisions and information relating to the person's care and wellbeing.

Carers NSW therefore believes that the experiences of carers of people with cognitive and psychiatric impairment who are indefinitely detained should be considered alongside the experiences of the individuals themselves.

c. the differing needs of individuals with various types of cognitive and psychiatric impairments such as foetal alcohol syndrome, intellectual disability or acquired brain injury and mental health disorders

Recognising the varying needs of people with diverse impairments is critical in providing adequate support. Establishing an individual's capacity to understand the information presented to them, make informed decisions and take responsibility for their actions are particularly important. Understanding the cause of disruptive behaviour is also important, as behaviour associated with intellectual disability and mental illness can be misinterpreted.

A key way in which the differing needs of individuals can be established is through communication with their carers, especially if a person has limited communication skills or lacks insight into their condition. Carers NSW believes that in cases where there are one or more carers, consultation should take place to ensure the person's condition and support needs are properly understood and addressed, and that an advocate is present if needed. Carers can inform those working with their loved one how to enhance

their communication, understand their actions and language and help to manage any disruptive behaviour.

h. access to justice for people with cognitive and psychiatric impairment, including the availability of assistance and advocacy support for defendants

Assistance and advocacy for people with cognitive and psychiatric impairments in the justice system is vitally important. In many cases, carers are already formally appointed substitute decision makers, or have established informal supported decision making arrangements with the person they care for. These arrangements should be supported and upheld wherever possible. Carers' views may also be helpful in determining the need, or level of need, for assistance and advocacy by other parties.

k. accessibility and efficacy of treatment for people who are a risk of harm to others and l. the use and regulation of restrictive practices and their impact on individuals with cognitive and psychiatric impairment

Carers' knowledge and experience may be useful in determining what risks of harm exist and how these may be mitigated, especially without resorting to restrictive practices. Carers are able to advise on particular triggers that may cause disruptive behaviour, and alternatives to these triggers. Carers NSW also believes that carers should be consulted and informed if restrictive practices are being considered. Models with proven efficacy, such as the 'Top 5' project implemented within NSW Health to manage the behaviour of people with cognitive impairments, may have useful application within detention settings.

m. the impact of the introduction and application of the National Disability Insurance Scheme (NDIS), including the ability of individuals with cognitive and psychiatric impairment to receive support under the NDIS while in detention

The scope of NDIS plans for carer support are limited, however funded supports are expected to have a respite effect for carers by reducing their caring role. Carers also have the opportunity to make a statement about how their caring role affects them, and some supports may be funded for the purpose of sustaining the caring role, such as training on a person's disability or counselling to deal with challenging behaviours.⁴

The National Disability Insurance Agency (NDIA) must ensure that carers are not invisible when the person they care for is detained. Carers who are involved in supporting NDIS participants should always be given the opportunity to be involved in the planning process, if the participant agrees, and to provide a carer statement. Planners should also consider that carers of people who are indefinitely detained may still need support during the period of detention, and that adequate carer support after detention may enable reconciliation with carers, where necessary, and help prevent the person reoffending.⁵

Policies and processes regarding the release of people with cognitive impairments who have been indefinitely detained, must include working with the NDIA to ensure appropriate supports are established prior to release. Utilising the NDIS effectively to provide the services someone may need upon their release may result in decreased recidivism and will reduce the stress and demands that would otherwise be placed on their carers.

n. the prevalence and impact of indefinite detention of individuals with cognitive and psychiatric impairment from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds, including the use of culturally appropriate responses

It has been well established that Aboriginal people are over-represented in the criminal justice system, and the indefinite detention of Aboriginal and Torres Strait Islander peoples with cognitive and psychiatric impairments has been identified as key human rights issue.⁶ Australian research has demonstrated that early, holistic support is crucial to prevent people with mental health disorders and cognitive impairment (particularly Aboriginal children and young people and those from disadvantaged backgrounds) from cycling in and out of the criminal justice system.⁷

Carers NSW joins calls to provide early support Aboriginal and Torres Strait Islander people with cognitive and psychiatric impairment in order to divert them from the criminal justice system, and asserts that this support should also be extended to the family who provide care to them, and who have a crucial role to play in their ongoing wellbeing.

Carers of people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds who are detained indefinitely will also need tailored information and support to enable them to navigate the system, understand their changed role and care for themselves.

Thank you for accepting our submission. For further information, please contact Sarah Judd, Senior Policy and Development Officer,

Yours sincerely,

Elena Katrakis
CEO
Carers NSW

¹ Australian Bureau of Statistics (2014) *Disability, Ageing and Carers, Australia: New South Wales, 2012*. Catalogue no. 4430.1.40.001. The Survey does not address cognitive and psychiatric impairment as a discrete category.

² Conversation with BEING, 30 March 2016.

³ Loucks, N. (2004) *Prison without bars: Needs, support and good practice for work with prisoners' families*. Tayside Criminal Justice Partnership and Families Outside, Scotland; McCann, G., McKeown, M. and Porter, I. (1996) 'Understanding the needs of relatives of patients within a special hospital for mentally disordered offenders: a basis for improved services', *Journal of Advanced Nursing*, 23: 346-352.

⁴ Carers NSW (2014) *The NDIS one year in: Experiences of carers in the Hunter trial site*. Carers NSW, Sydney.

⁵ McCann *et al* (1996); Riches, V.C. Parmenter T.R. Wiese, M. and Stancliffe, R. J. (2006) 'Intellectual disability and mental illness in the NSW criminal justice system', *International Journal of Law and Psychiatry*, 29: 386–396.

⁶ Australian Human Rights Commission (2015) *Factsheet: Criminal Justice System*, accessed at <https://www.humanrights.gov.au/sites/default/files/17.%20Criminal%20Justice%20System%20Final.pdf> on 30 March 2016.

⁷ McCausland, R., Johnson, S, Baldry E. and Cohen, A. (2013) *People with mental health disorders and cognitive impairment in the criminal justice system: cost-benefit analysis of early support and diversion*, Price Waterhouse Coopers & University of New South Wales, Sydney.