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Associate Professor JULIAN TROLLOR

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David Coyne Director, Office of the Senior Practitioner NSW Department of Ageing Disability & Home Care Level 4, 93 George Street Parramatta NSW 2150

Dear David,

Thank you for asking me to provide advice to the Office of The Senior Practitioner related to the complexities of care provision for a small number of severely disturbed individuals with intellectual disability. In providing this advice please be aware that the content represents my opinion only, that I have no specific legal or forensic mental health training, and that I am relying on my clinical experience and discussions over time with stakeholders, colleagues and consumers.

The verbal briefing provided two weeks ago by you and Matt Frize highlighted concerns that have arisen in the management of complex individuals with intellectual disability, some of which are known to me. These individuals are characterised by mild-moderate levels of intellectual disability, poor impulse control and severe personality disorder (usually borderline). Some have had extensive contact with the criminal justice system. Almost invariably, these individuals present high ongoing risk to themselves through deliberate self harm behaviours and risk to the community of impulsive and unpredictable aggression toward property and individuals. The cases raise three issues related to care and treatment in the NSW setting: 1) Do we have an optimal legislative framework of care? 2) Do we have appropriate treatment facilities? 3) Do we have appropriate treatment models and staff expertise?

Legislative Framework

As in other States of Australia, the NSW Mental Health Act (2007) does not include intellectual disability within the definition of mental illness. A person with intellectual disability and personality disorder who is in an acute crisis and at immediate risk of harming self or others may be detainable for crisis containment only in a mental health facility as a "Mentally Disordered Person" within the meaning of the NSW Mental Health Act. However, this Act does not provide for situations in which people with intellectual disability and personality disorder require ongoing coercive treatment.

Although the Disability Services Act (1993) sets out the provision of services to individuals with intellectual disability through appropriate funding, facilities and governance, the Act itself does not deal with the complex issue of care and containment of people with intellectual disability. The NSW Guardianship Act (1987) includes intellectual disability as one aspect fulfilling the definition of disability, and contains provision for decisions to be made about financial management, medical care and accommodation.

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The Guardianship legislation does not specifically address the issue of individuals with intellectual disability and high risk behaviours or personality disorder, but these are considerations made by an appointed Guardian when making substitute decisions. The Guardianship legislation does not specifically address the issue of individuals with intellectual disability who have been charged with an offence.

The Mental Health (Forensic Provisions) Act 1990 contains provision for a person, including someone with intellectual disability who is found "unfit to plead" or "not guilty dues to mental illness" to be referred to the Mental Health Tribunal. Recommendations to the court or decisions regarding care and treatment are then made. This is one potential pathway for individuals with intellectual disability and either mental illness or severe personality disorder to be referred to an appropriate secure treatment facility. However, beyond the forensic stay, the person may then present an ongoing challenge and risk.

In some other jurisdictions, for example in Victoria, the Disability Act (2006) provides for the specific proclamation of premises and programs as "residential treatment facilities" for the purposes of compulsory treatment. Providing all less restrictive options have been exhausted, a person with an intellectual disability may be admitted if they present a serious risk of violence to another person. A focus on the therapeutic nature of such detainment is contained within the Act, in that an authorised program officer must prepare a treatment plan within 28 days of admission to such a facility, which is reviewed initially at 6 months and then annually. There is also a Multiple and Complex Needs Initiative (MACNI) which brings together a funded interdisciplinary and interdepartmental response to such individuals http://www.dhs.vic.gov.au/operations/multiple-and-complex-needs-unit.

Comment

- The current legal framework in NSW poses a challenge particularly in reference to individuals with intellectual disability and severe personality disorder exiting the forensic system.
- The current reliance on the Guardianship Act places the burden for decision making relating to highly complex risk issues on the Guardian.
- In NSW, outside of the forensic system, the specific 'risk' issues in the types of individuals you described to me are potentially more difficult to contain and monitor, as there is no specific legislative framework which deals with this risk and no specific legal framework which specifies a review process within a residential care facility.

Suggested action

- It would be useful to seek the opinion of the Public Guardian, on the advantages or disadvantages of alternative models such as the Victorian legislative framework.
- Broader consultation with the Department of Justice and Attorney General may be advisable.

Treatment Facilities, Treatment Models and Expertise

The ideal treatment facility is one which is purpose designed, close to (or integrated with) mainstream disability and health services and large enough to support a critical mass of expert

staff. Such a facility would ideally have a broader focus than the cases described above. For example the facility could incorporate a tertiary inpatient unit for assessment of people with intellectual disability and complex mental illness. The ideal treatment model would bring together a holistic, evidence based framework of care which was inclusive of (a) the neuropsychiatric understanding of brain-behaviour relationships, (b) a sophisticated psychological approach based on cognitive behaviour therapy (CBT), dialectic behaviour therapy (DBT) and other appropriate therapies (c) well developed social models of care and (d) consideration of the often complex general health needs of this population. Such facilities are available in the UK, and involve relentless positive programming, and a strong recovery focus, acknowledging that many people admitted to such a facility have had extremely pejorative early life experiences. Such a facility would be enriched by strong evaluation of outcomes, adherence to quality assurance standards and strong commitment to staff training.

Comment

- We do not have such a facility in NSW or indeed in my knowledge in Australia.
- Discussions in which I have taken part around existing 'problem' cases have highlighted a lack of skilled staff in the specific ADHC residences, who appear to be functioning somewhat remotely from mainstream services or supports.
- Discussions with a number of potential stakeholders suggest that there is interest in investigating a specific intellectual disability mental health facility.

Suggested action

- Further scoping work in regard to models of care and treatment facilities is recommended.
- Wider consultation regarding the possibility of a funded secure unit as above.

Overall, the intersection between intellectual disability, personality disorder, mental health and offending or at risk behaviour represents one of the most challenging in the field of care for this group. I would highly recommend that these issues are taken forward in service development, clinical and research forums. For example, this is one issue that could be put on the agenda of the new Intellectual Disability Health Network (NSW Health Agency for Clinical Innovation), and discussed at a variety of health and disability forums such as the AADDM 2012 Conference here at UNSW.

I would be pleased to discuss any issues raised in more detail with you.

Sincerely,

Associate Professor Julian Trollor

Chair, Intellectual Disability Mental Health

Head, Department of Developmental Disability Neuropsychiatry