



A/PROF JULIAN TROLLOR
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Dear Mr Chris Harrigan,

As the Chair of Intellectual Disability Mental Health and Head of the Department of Developmental Disability Neuropsychiatry (3DN) at the University of New South Wales I would like to take this opportunity to share my team's aspirations for an enhanced acknowledgement within the Practice Standards, and inclusion in the proposed national core competencies of the essential workforce attributes required to meet the mental health needs of people with an intellectual disability (ID).

Our department aims to improve the mental health of people with an ID via three strategic approaches: i) Education and Training, ii) Service Development, and iii) Research. Examples of our current work relating to workforce development include the:

- Engagement of the Department of Health and Ageing regarding a proposed National Intellectual Disability Mental Health Service Guideline and National Intellectual Disability Mental Health Round Table.
- Development and implementation of core competences in IDMH for the Child and Adolescent Mental Health workforce in NSW.
- Development of an on-line educational tool to facilitate continuing professional development in IDMH for all front-line mental health staff.
- An audit of IDMH content within medical and registered nursing undergraduate courses and psychiatric traineeships.

Background: Intellectual Disability Mental Health

Over 400,000 Australians have an ID [1, 2] and the majority of these individuals (57%) have a psychiatric disability or mental disorder [3]. Compared to the general population, health surveys have revealed that people with ID experience very poor health status, characterised by higher mortality [4, 5], and elevated rates of common mental disorders at 2-3 times that of the general population [6-10] including schizophrenia [11], affective disorders and anxiety disorders and the dementias [12-15]. However, despite both the frequency and complexity of their mental health care needs people with an ID experience significantly lower rates of participation in preventative health initiatives, illness and disease detection, and treatment of mental health problems [7, 16-18].

One of the significant contributors to this population's inequitable access to mental health care is an ill-equipped mental health workforce. The lack of training opportunities and the

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absence of standards and core competencies in this area are contributing factors to the lack of the skills, knowledge and confidence reported by the mental health workforce when working with people with a dual diagnosis of ID and mental disorder [19-26].

For Australia to uphold both its national and international commitments, as described in the National Disability Strategy 2010-2020 [27] and the Convention on the Rights of Persons with Disabilities (CRPD) [28] it is essential that action is taken to address the current limitations of the mental health workforce. The need for such action has been widely endorsed by key stakeholders across Australia in a recent position statement on the place of people with intellectual disability in mental health reform [29].

Practice Standards Review – An IDMH perspective

We commend the current Practice Standards for fostering a human rights approach to service delivery, and for directly and indirectly acknowledging individuals with an intellectual disability. However, the current scope of the Practice Standards and the broad terminology used to refer to this significant minority group has unfortunately had minimal impact on achieving its stated applications. For example there is currently:

- minimal IDMH content within undergraduate medical and registered nursing curriculum,
- very limited availability of specialised trainee positions for psychiatrists in ID,
- a lack of postgraduate and continuing professional development opportunities in this area for the five key professional groups,
- a lack of specific core competencies in IDMH, and
- an absence of credentialing within this area.

As such, we propose the following amendments to the Practice Standards:

1. *An additional standard dedicated to the skills, knowledge, attitudes and values required to deliver accessible and quality mental health services to people with ID.*

Although people with an ID and may require highly specialised mental health care their support needs can readily be accommodated by mainstream services if the workforce receives adequate training and support in this area.

An additional standard would facilitate:

- an essential link with the Fourth National Mental Health Plan[30] which highlights the urgent need to address mental disorders in this group, and to do so in an inclusive manner,
- acknowledge and highlight the particular vulnerabilities and complex needs of this group, and
- provide a much needed framework upon which core competencies and workforce education could be based.

2. *Enhancement to current practice standards*

The content of the current practice standards could be enhanced by an acknowledgement of:

- the principles and values of the Convention on the Rights of Persons with Disabilities (CRPD),
- the importance of being able to work competently and confidently with people with complex communication needs,
- an ability to adapt the diagnostic process and interventions appropriate to the persons' abilities,
- diagnostic overshadowing and the role that it may have on both the identification and diagnosis of mental health issues,

- knowledge of support services available in the disability sector and the different roles and responsibilities of the disability and health service sectors,
- the importance of the engagement and working with support persons, both within paid and unpaid roles across both health, mental health and the disability service sector,
- attitudes relating to people with an ID and their experience of poor mental health,
- the philosophy of 'nothing about us without us' to facilitate the inclusion and participation of people with ID in the development and evaluation of services, and
- the need to collect and report on data relating specifically to people with an ID.

The language of the current practice standards could be enhanced by:

- directly referring to people with an ID when describing minority groups with complex needs, and
- Utilising the terminology support person or advocate instead of carer.

HWA National Core Competencies Project

As described above there is a range of workforce attributes that are essential for delivering effective, efficient and accessible healthcare to people with an ID. We recommend the inclusion of such attributes within the proposed common core competencies as they may play an important role in not only improving health care for people with an ID but also other individuals with complex communication and health care needs, and vulnerabilities requiring proactive healthcare and advocacy.

We have recently commenced the development of ID mental health core competencies and have identified the following resources which may provide useful examples for Health Workforce Australia's project. These include:

- The disability component of the Royal Australian College of General Practitioners Curriculum for Australian General Practice [31]
- The Resource Manual in Dual Diagnosis, Victorian Dual Disability Service [32]
- A mental health care pathway for children and young people with learning disabilities: A resource pack for service planners and practitioners – Section C: Developing Practitioners Skills [33]
- Core Competencies Required for Child Psychiatrists training in Learning Disability (Appendix 4) [34]
- Core areas and knowledge and skills required of nurses working in the area of intellectual disability mental health [35]
- Competence Profile for Intellectual Disability Physicians [36]

Should you wish to discuss the content of this letter please do not hesitate to contact me to organise a convenient time for a meeting or teleconference. I can be contacted by phone on (02) 9931 9160 or by email, j.trollor@unsw.edu.au.

Yours sincerely,



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References:

1. Begg, S., et al., *The burden of disease and injury in Australia 2003*. PHE 82., 2007, AIHW: Canberra.
2. Australian Bureau of Statistics. *Australian Demographic Statistics, Table 07, Estimated resident population, Age groups - Australia - at 30 June. Time series spreadsheet, Cat. no. 3101.0.001*. 2009.
3. Australian Bureau of Statistics, *Disability: Ageing and Carers Australia: Summary of Findings, Ageing and Carers: Summary of Findings 2009*, Cat no. 44300 2010, ABS: Canberra.
4. Bittles, A.H., et al., *The influence of intellectual disability on life expectancy*. Journals of Gerontology Series A-Biological Sciences & Medical Sciences, 2002. **57**(7): p. M470-2.
5. Patja, K., et al., *Life expectancy of people with intellectual disability: a 35-year follow-up study*. Journal of Intellectual Disability Research, 2000. **44**(Pt 5): p. 591-9.
6. Cooper, S.A., et al., *Mental ill-health in adults with intellectual disabilities: prevalence and associated factors*. British Journal of Psychiatry, 2007. **190**: p. 27-35.
7. Einfeld, S.L., et al., *Psychopathology in Young People With Intellectual Disability*. JAMA: The Journal of the American Medical Association, 2006. **296**(16): p. 1981-1989.
8. Smiley, E., et al., *Incidence and predictors of mental ill-health in adults with intellectual disabilities: prospective study*. British Journal of Psychiatry, 2007. **191**: p. 313-9.
9. Einfeld, S.L., L.A. Ellis, and E. Emerson, *Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review*. Journal of Intellectual & Developmental Disability, 2011. **36**(2): p. 137-43.
10. Emerson, E. and C. Hatton, *Mental health of children and adolescents with intellectual disabilities in Britain*. The British Journal of Psychiatry, 2007. **191**(6): p. 493-499.
11. Borthwick-Duffy, S.A., *Epidemiology and prevalence of psychopathology in people with mental retardation*. Journal of Consulting and Clinical Psychology, 1994. **62**(1): p. 17-27.
12. Cooper, S.A., *High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome*. Psychological Medicine, 1997. **27**(3): p. 609-16.
13. Cooper, S.A. and A. Holland, *Dementia and mental ill-health in older people with intellectual disabilities*, in *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*, N. Bouras and G. Holt, Editors. 2007, Cambridge University Press: Cambridge, UK.
14. Strydom, A., et al., *Report on the State of Science on Dementia in People with Intellectual Disabilities*, 2009, IASSID SIRG on Ageing and Intellectual Disabilities.
15. Strydom, A., et al., *Prevalence of dementia in intellectual disability using different diagnostic criteria*. British Journal of Psychiatry, 2007. **191**: p. 150-7.
16. Dekker, M.C. and H.M. Koot, *DSM-IV disorders in children with borderline to moderate intellectual disability. I: prevalence and impact*. Journal of the American Academy of Child & Adolescent Psychiatry, 2003. **42**(8): p. 915-22.
17. McCarthy, J. and J. Boyd, *Mental health services and young people with intellectual disability: is it time to do better?* Journal of Intellectual Disability Research, 2002. **46**(3): p. 250-256.
18. Beange, H., A. McElduff, and W. Baker, *Medical disorders of adults with mental retardation: A population study*. American Journal on Mental Retardation, 1995. **99**(6): p. 595-604.

19. Phillips, A., J. Morrison, and R.W. Davis, *General practitioners' educational needs in intellectual disability health*. Journal of Intellectual Disability Research, 2004. **48**(Pt 2): p. 142-9.
20. Edwards, N., N. Lennox, and P. White, *Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability*. Journal of Intellectual Disability Research, 2007. **51**(Pt 1): p. 75-81.
21. Lennox, N.G., J.N. Diggins, and A.M. Ugoni, *The general practice care of people with intellectual disability: barriers and solutions*. Journal of Intellectual Disability Research, 1997. **41**(Pt 5): p. 380-90.
22. Lennox, N. and R. Chaplin, *The psychiatric care of people with intellectual disabilities: the perceptions of trainee psychiatrists and psychiatric medical officers*. Australian & New Zealand Journal of Psychiatry, 1995. **29**(4): p. 632-637.
23. Lennox, N., J.N. Diggins, and A.M. Ugoni, *Health care for people with an intellectual disability: General Practitioners' attitudes, and provision of care*. Journal of Intellectual & Developmental Disability, 2000. **25**(2): p. 127-133.
24. Mohr, C., et al., *Interagency training in dual disability*. Australian Psychiatry, 2002. **10**(4): p. 356-364.
25. Lennox, N. and R. Chaplin, *The psychiatric care of people with disabilities: the perceptions of consultant psychiatrists in Victoria*. Australian & New Zealand Journal of Psychiatry, 1996. **30**(6): p. 774-780.
26. Jess, G., et al., *Specialist versus generic models of psychiatry training and service provision for people with Intellectual disabilities*. Journal of Applied Research in Intellectual Disabilities, 2008. **21**: p. 183-193.
27. Council of Australian Governments, *National Disability Strategy 2010-2020*, 2011, Commonwealth of Australia: Canberra.
28. United Nations, *Convention on the Rights of Persons with Disabilities*, 2006, United Nations: Geneva.
29. National & NSW Councils for Intellectual Disability and Australian Association of Developmental Disability Medicine. *The place of people with intellectual disability in mental health reform*. 2011 11/9/12]; Available from: www.nswcid.org.au/images/pdfs/idmh1011.pdf.
30. Department of Health and Ageing, *Fourth National Mental Health Plan - An agenda for collaborative government action in mental health 2009 - 2014.*, 2009, Department of Health and Ageing: Canberra, Commonwealth of Australia.
31. The Royal Australian College of General Practitioners, *The RACGP Curriculum for Australian General Practice: Disability*, 2007, The Royal Australian College of General Practitioners.
32. Victorian Dual Disability Service, *Resource Manual in Dual Disability*, 2001, The Department of Human Services: Victoria.
33. Pote, H. and D. Goodban, *A mental health care pathway for children and young people with learning disabilities: A resource pack for service planners and practitioners*, J. Bureau, Editor 2007, CAMHS Evidence-Based Practice Unit, London.
34. The College of Psychiatry of Ireland, *Position Paper: Mental Health Provision for Children with a Learning Disability*, 2011, The College of Psychiatry of Ireland: Ireland.
35. Higgins, S., *The mental health needs of people with severe learning disabilities*. British journal of nursing (Mark Allen Publishing), 2004. **13**(22): p. 1342-6.
36. NVAVG, *Competence Profile for ID Physician*, 2006, NVAVG: The Netherlands.