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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

UNSW



ASSOCIATE PROFESSOR
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Department of Developmental Disability Neuropsychiatry

Dear Committee Members,

Commonwealth Funding and Administration of Mental Health Services

Please find attached our submission calling on the Commonwealth to better accommodate and support the mental health needs of people with an intellectual disability in the funding and administration of Mental Health Services.

I am writing to you on behalf of the Department of Developmental Disability Neuropsychiatry at UNSW to urge that the Commonwealth Government take leadership to ensure that current service provision, policy development and mental health service expansion under the 2011 Mental Health Budget extends to, and includes people with an intellectual disability. I write this submission also in my role as the Chair of Intellectual Disability Mental Health here in NSW, as a clinician with multiple years of experience working in the field of intellectual disability mental health and as a concerned citizen with an interest in increasing the equity of health service provision.

We believe that the 2011 Commonwealth Budget for Mental Health lacks emphasis on the high burden of mental ill health experienced by people with intellectual disability, and lacks specific strategies to target the difficulties that this population experiences in accessing appropriate mental health supports. As this submission will highlight, there are opportunities within the 2011 Commonwealth Budget on Mental Health to extend Mental Health service provision and policy development such that it is inclusive of people with an intellectual disability. The 2011 Commonwealth Budget for Mental Health presents a positive opportunity to fulfil Australia's obligations as signatory to the UN Convention on the Rights of Persons with Disabilities (Appendix 2), which are 'to provide accessible health care to people with intellectual disabilities.'

We thank you for the opportunity to provide comment in this Senate Inquiry into the Commonwealth Funding and Administration of Mental Health Services and trust you will consider the suggestions herein in enhancing the funding and administration of mental health services for people with intellectual disability. Should you wish to discuss this further, please contact myself on Ph) 9931 9160 or email at j.trollor@unsw.edu.au.

Yours sincerely,

Julian Trollor

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Senate Community Affairs Committee
Commonwealth Funding and Administration of Mental Health Services

Summary

Approximately 408,000 Australians (1.8% of the population) have an intellectual disability (ID). This number is of similar magnitude to the indigenous population, but despite the impoverished mental and physical health of people with ID, their health status receives comparatively little attention. Mental disorders are at least two and a half times more common in people with ID compared to the general population. Australian research has demonstrated the inaccessibility of mental health services for people with ID. In a fourteen year period, only 10% of persons with ID and a mental disorder had received a mental health intervention (Einfeld & Tonge 1996; Einfeld et al., 2006). By contrast, in the general population, 34.9% of the people with mental disorders receive treatment in a twelve month period (Burgess et al. 2009).

The poor mental health status and inaccessibility of mental health supports for people with ID is caused by a number of different factors. Many people with ID, especially those with complex or severe developmental disabilities, experience an atypical profile and the presentation of mental disorders thus requires a high level of psychiatric expertise. However, appropriately skilled and resourced primary health care practitioners, community mental health teams, specialist mental health practitioners and specialist acute inpatient mental health facilities are lacking. The current situation comes at great human and financial cost to people with ID and their families, as well as considerable financial cost to the health, social security, criminal justice and disability service systems.

While we commend the Commonwealth Government for making Mental Health the centrepiece of the 2011 Budget, we do feel that the mental health needs of people with intellectual disability have been ignored to date. We would like the investment that is being made to improve the nation's mental health to include people with ID, whose mental illnesses often go undiagnosed and untreated. We urge the Commonwealth Government to increase the level of commitment to, and inclusion of, the mental health care needs of people with an intellectual disability in the 2011 Mental Health Budget.

This submission of the Department of Developmental Disability Neuropsychiatry, University of New South Wales urges the Commonwealth Government to take action on improving the mental health care needs of people with intellectual disability. We recommend that the following actions are taken as a result of this Senate Inquiry into Commonwealth Funding and Administration of Mental Health Services, they are:

- 1) That targets are set in Mental Health Reform Budget 2011-12, and beyond, for improving the inequity in mental health service provision for people with ID.
- 2) That the impact of the changes to the Better Access Initiative on people with ID is further investigated. We request especially that the introduction of the two-tiered system of rebates is investigated to prove that this has no negative repercussions on access to mental health treatment for people with ID.
- 3) That incentives are provided to Divisions of General Practitioners (GPs) under the ATAPS Program for demonstrating efficacy in innovatively meeting the mental health needs of people with ID.
- 4) That evidence is provided that the ATAPS Program positively improves access to mental health services for people with ID. Alternatively, that Divisions of GPs are required to

report on their efficacy in reaching people with ID, and that this is championed highly in terms of innovative service delivery.

- 5) That the Commonwealth takes leadership in establishing specialist multidisciplinary intellectual disability mental health services, in order to raise awareness and training capabilities, and establish improvements in referral and triage services.
- 6) That people with ID receive a level of support and funding that boosts the service system to adequately meet the mental health needs of this population group.
- 7) That the mental health care needs of people with an ID will be included within the remit of the National Mental Health Commission.
- 8) That any further development of online mental health services, such as an e-health portal, is designed in a manner that promotes access for people with ID and that this specific comorbidity is incorporated into the expansion of the e-health program.

And that overall,

- 9) The Commonwealth takes leadership to ensure that people with ID are included in future mental health service expansion, and are considered integral in the National Ten Year Roadmap for Mental Health Reform.
- 10) That the needs of this population group are specified in any policy, service development and any future budget plans such that, the needs of this marginalised group are not overlooked into the future.

Response to Senate Inquiry Terms of Reference

a) The Government's 2011-12 Budget changes relating to mental health

We commend the Commonwealth Government for making Mental Health the centrepiece of the 2011 Budget. Investing in the mental health of the nation is both sound and wise and should not be considered as secondary to establishing broader health reform, but integral to it. We would prefer however that this great opportunity, in developing the mental health care infrastructure, also incorporates the needs of people with intellectual disability (ID). People with ID have been identified as a disadvantaged group with complex needs in the Fourth National Mental Health Strategy 2009, in the National Mental Health Plan as well as the Council of Australian Governments Action Plan on Mental Health 2006-2011. Each of these Plans document the need for improved integration and coordination of services for people with these complex needs. However, despite the expressed need for improved coordination and integration of services for people with these complex needs, commitment to improving the equity of service provision to this group is still largely undemonstrated. We feel that a strong commitment to the needs of people with ID would be evidenced by funding for specialist multidisciplinary services for intellectual disability mental health; targeting funding at training that improves joint referral and triage services at a national level; and improving training and awareness at the clinical and service staff level.

Commonwealth policy, service development and budgets have to date, failed to demonstrate any real targets in relation to this population. We feel this reflects a lack of true commitment to proactive service and policy development for people with ID and that such a focus is necessary at a National level if the mental health inequity of this group is to be truly redressed.

b) Changes to the Better Access Initiative, including:

- (i) the rationalisation of general practitioner (GP) mental health services,
- (ii) the rationalisation of allied health treatment sessions,
- (iii) the impact of changes to the Medicare rebates and the two-tiered rebate structure for clinical assessment and preparation of a care plan by GPs, and
- (iv) the impact of changes to the number of allied mental health treatment services for patients with mild or moderate mental illness under the Medicare Benefits Schedule

We are concerned that the introduction of the two-tiered Medicare rebate system for psychologists will have a significant impact on accessible of services for people with ID who largely receive their mental health care treatment and referrals to clinical and non-clinical Psychologists via General Practitioners. There are currently few Psychologists working in the speciality area of intellectual disability mental health and it is our concern that this tiered system of access would serve to further reduce this pool of specialist Psychologists by making it virtually impossible for them to continue to earn a living treating this clientele.

We request that as part of the changes to the Better Access Initiative, the Commonwealth Government undertake thorough investigations to determine the impact that these changes will have specifically on the mental health needs of people with ID.

c) The impact and adequacy of services provided to people with mental illness through the Access to Allied Psychological Services (ATAPS) program

We commend the Commonwealth Government for extending the Access to Allied Psychological Services (ATAPS) program. We recognise that the reforms of the Program have

been set up to reward fiscal responsibility on behalf of the Divisions of General Practitioners (GPs), as well as to reward them for their ability to innovatively target hard to reach populations. However, we have reservations that the specific mental health needs of the subset of the population with ID are adequately catered for under this universal model of service provision. Evidence suggests that GPs already have limited levels of awareness of the mental health needs of people with ID (Phillips et al. 2004), which indicates that unless stipulated to, the Divisions, and GPs themselves, would not consider people with ID in their outreach programs. We wish to see more evidence documenting that the expansion of this Program has a positive impact on improving access to mental health services for people with ID. We would like to see how people with ID are accessing these services. Alternatively, we request that Divisions of GPs are required to report on their efficacy in reaching people with an ID, and that this is championed highly in terms of innovative service delivery.

d) Services available for people with severe mental illness and the coordination of those services

Despite the commitment to improved coordination and integration of services expressed in the Fourth National Mental Health Strategy and National Mental Health Plan, as well as in the COAG Action Plan on Mental Health 2006-2011, there is little evidence of this to date. Similarly, the COAG National Disability Strategy 2010 – 2020 committed all Australian Governments to ‘interconnectivity’ with the view to improving the health and wellbeing of people with disabilities. The needs of people suffering from mental health disorders intersect across a range of Government sectors, such as health and disability and this needs to formally be recognised by flexible service delivery and policy.

Issues

Dual diagnoses in general are not well accommodated in this Budget, such as comorbid mental illness and substance use disorders, and comorbid intellectual disability and mental illness. This client group with complex needs are the most marginalised in our society and leadership that sees an end to the dichotomising of people’s issues according to strict bureaucratic boundaries is long overdue. What is required is a multidisciplinary approach to the provision of health services in general and mental health services more specifically. People with ID are currently very poorly serviced across mental health, health and disability service sectors and fall through the gaps as a consequence.

Currently, clinical and disability service staff have little expertise in effectively treating mental illness in people with ID. This often results in great human cost to people with intellectual disability and their families. It also results in considerable financial cost to the health and disability services in terms of high rates of readmissions, long length of stay, and time in triage and consultation in a system currently ill-equipped to easily accommodate these needs. With greater investment in improving coordination these costs would substantially reduce. This would have run on cost reductions for other government services which are impacted on by the current poor coordination of services, such as the justice system¹.

Solutions

As a means of improving coordination, we consider that these two solutions will greatly improve the coordination of mental health services for people with ID:

- i. The establishment of a centre of excellence in Intellectual Disability Mental Health Training and Research

¹ According to a NSW Law Reform Commission Report (2003) there is an over-representation of people with an intellectual disability both as victims and offenders in the criminal justice system.

We attribute poor service coordination largely to a lack of training, expertise and experience in the appropriate triage and referral processes for people with such complex needs. This lack of training or experience may lead clinicians to assume that the symptoms that a person with ID is experiencing are part of the disability and not a separate health condition that requires treatment. The funding of such a facility would support national curriculum and training programs in intellectual disability mental health which would provide a backbone for development of a workforce in intellectual disability mental health.

- ii. **Specialist Multidisciplinary Intellectual Disability Mental Health Units**
Access to these specialist multidisciplinary health and mental health services are required across all States. These services could provide expert review and advice to support clinicians in primary health and specialist sectors.

e) Mental health workforce issues, including:
(i) the two-tiered Medicare rebate system for psychologists,
(ii) workforce qualifications and training of psychologists, and
(iii) workforce shortages

Australia has a significant skills shortage in intellectual disability mental health. Australian research indicates that GPs, Psychiatrists and trainees lack confidence and training in relation to people with ID and mental disorders, and consider that people with ID and mental disorders receive a poor standard of care and that community mental health supports are inadequate (Cook and Lennox 2000; Lennox and Chaplin 1995; Lennox and Chaplin 1996; Lennox, Diggins and Ugoni 1997; Phillips, Morrison & Davis 2004; Edwards, Lennox & White 2007; Jess et al. 2008). Only isolated pockets of expertise in intellectual disability mental health exist in Australia. Within the public mental health service across Australia there are no full-time staff specialist positions devoted to this need and only a handful of nursing positions within the public mental health sector. There is one recently established academic Chair of Intellectual Disability Mental Health at the University of NSW. A number of advanced traineeships are available through the NSW Institute of Psychiatry, but the lack of identifiable specialist positions post-training has made it hard to recruit trainees. By contrast, in the UK, there is a well-developed specialty in intellectual disability mental health, which promotes clinical confidence and competence and which sets a strong research and continuing education agenda. Mental health clinical staff in the UK express confidence in their knowledge and training in this area, which is a stark contrast to that found in Australia (Jess et al., 2008).

As stated above, we recommend the establishment of specialist multidisciplinary intellectual disability mental health services. These would not only dramatically improve the management, treatment and referral process for people with ID who have mental disorders, but would also serve to build capacity and improve training in the mental health sector. These services would be able to act as a consultancy and training resource to primary mental health care services. It would also put Australia in line with the UK, in terms of leading the way in intellectual disability mental health care and would be well in line with the commitments to the health of people with disabilities as made in the ratification of the UN Convention on the Rights of Persons with Disability (Appendix 2).

f) The adequacy of mental health funding and services for disadvantaged groups, including:
(i) culturally and linguistically diverse communities,
(ii) Indigenous communities, and
(iii) people with disabilities

We consider mental health funding for disadvantaged groups, such as people with ID to be inadequate at current levels. We are calling on the Commonwealth to consider the need to extend the investment in mental health to better accommodate these groups, all of whom have complex needs that current funding cannot address. Based on population statistics and available prevalence estimates of mental disorders in people with ID, the current funding for services for people with ID and mental ill health falls far below expectations. In Australia, just under 2% of the population (408,000 individuals) has an intellectual disability. The point prevalence of mental illness in this group has been estimated to be about 40% (Cooper et al., 2007). In order to meet such high needs, a significant proportion of the overall mental health budget would need to be spent on intellectual disability mental health. It is our view that the lack of strategic thinking, proactive policy development and funding by Government in this area has contributed to the current situation whereby this group of the population fall though the service gaps. We firmly recommend that intellectual disability mental health receives increased support and funding from the 2011 Mental Health Budget.

g) The delivery of a national mental health commission

We welcome the decision to establish a National Mental Health Commission as a mechanism for improving accountability in the provision of mental health services. We do however require evidence confirming that the mental health care needs of people with ID will be included within the remit of the National Mental Health Commission.

We request that:

- the mental health needs of people with ID are a specific focus of the Commission and that,
- the Commission recognises the health inequity of people with ID and advocate at a national level for strategic improvements on their behalf.

h) The impact of online services for people with a mental illness, with particular regard to those living in rural and remote locations and other hard to reach groups

We support the additional funding for e-health services to help people in remote and rural locations. However, it is not clear how this service enhancement would benefit the mental health needs of people with ID. We encourage the Commonwealth Government to undertake a review that ascertains the benefits of e-mental health services for people with ID and that this specific comorbidity is incorporated into the expansion of the e-health program. Further, we request that the development of any e- mental health portal or online services for people in remote areas is designed in a manner that promotes easy access for people with ID.

i) Any other related matter.

We request that the Commonwealth Government take leadership on ensuring that people with ID are included in future mental health service expansion, and are considered integral in the

National Ten Year Roadmap for Mental Health Reform. Currently the acknowledgement that people with intellectual disability receive in the 2011 Budget is restricted to the term 'people with complex needs' which does not adequately draw attention to the specific needs of this group. We feel that leadership at a national level would significantly help to raise the clinical profile of this group and help in treating the mental health issues of this group in the future. Also by failing to identify what 'complex needs' specifically refers to, we have concerns about the level of accountability of mental health services in trying to meet such 'needs'.

We urge the Commonwealth to specify the needs of this group in any policy and service development and any future budget plans so that the needs of this marginalised group are not overlooked into the future. This will ensure not only that future services are held accountable to providing for this population, but also that Australia will become a custodian of equitable mental health services for its entire population. Once we can ensure that this disadvantaged population are able to receive the services they need, and services can acknowledge their needs, we will be able to stop them falling through service gaps as they currently are.

Recommendations

As a result of this Senate Inquiry into Commonwealth Funding and Administration of Mental Health Services, we would like to see the following recommendations accommodated in the 2011 Commonwealth Mental Health Budget, as follows:

- 1) That targets are set in Mental Health Reform Budget 2011-12, and beyond, for improving the inequity in mental health service provision for people with ID.
- 2) That the impact of the changes to the Better Access Initiative on people with ID is further investigated. We request especially that the introduction of the two-tiered system of rebates is investigated to prove that this has no negative repercussions on access to mental health treatment for people with ID.
- 3) That incentives are provided to Divisions of General Practitioners (GPs) under the ATAPS Program for demonstrating efficacy in innovatively meeting the mental health needs of people with ID.
- 4) That evidence is provided that the ATAPS Program positively improves access to mental health services for people with ID. Or that alternatively, the Divisions of GPs are required to report on their efficacy in reaching people with ID, and that this is championed highly in terms of innovative service delivery.
- 5) That the Commonwealth takes leadership in establishing specialist multidisciplinary intellectual disability mental health services, in order to raise awareness and training capabilities, and establish improvements in referral and triage services.
- 6) That people with ID receive a level of support and funding that boosts the service system to adequately meet the mental health needs of this population group.
- 7) That the mental health care needs of people with an ID will be included within the remit of the National Mental Health Commission.
- 8) That any further development of online mental health services, such as an e-health portal, is designed in a manner that promotes access for people with ID and that this specific comorbidity is incorporated into the expansion of the e-health program.

And that overall,

- 9) The Commonwealth takes leadership to ensure that people with ID are included in future mental health service expansion, and are considered integral in the National Ten Year Roadmap for Mental Health Reform.
- 10) That the needs of this population group are specified in any policy, service development and any future budget plans such that, the needs of this marginalised group are not overlooked into the future.

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Appendix 1

Details about the Submitting Organisation

Role of UNSW Chair of Intellectual Disability Mental Health and the Department of Developmental Disability Neuropsychiatry

Julian Trollor (MBBS, MD, FRANZCP) is a Neuropsychiatrist and holds the inaugural Chair of Intellectual Disability Mental Health. The Chair is funded by the Department of Human Services (Ageing, Disability and Home Care) and the Faculty of Medicine at UNSW. In 2009 A/Prof Trollor established the Department of Developmental Disability Neuropsychiatry and a tertiary clinic in Intellectual Disability Neuropsychiatry at Prince of Wales Hospital.

The Department aims to:

- enhance the workforce in intellectual disability mental health
- assist strategic planning of mental health services for persons with intellectual disability
- contribute to intellectual disability health policy development
- deliver clinical services
- develop research capacity
- devise and deliver teaching and training in mental health and intellectual disability.

A/Prof Trollor is actively seeking ways to improve service provision for people with intellectual disability. He is an effective researcher, being Investigator on grants totalling more than \$5M. His research programs include: ageing and cognitive decline in intellectual disability, intellectual disability in the criminal justice system, human rights & healthcare in intellectual disability, assessing attitudes and training needs in intellectual disability mental health, disability and health data linkage for persons with intellectual disability and ageing studies in the general population. A/Prof. Trollor currently supervises or co-supervises 7 PhD students, provides mentorship and supervision to post-doctoral researchers within Brain and Ageing Research Program, psychiatric registrars and advanced trainees in Intellectual Disability Mental Health. A/Prof Trollor is the current Secretary-Treasurer and President-elect of the International Neuropsychiatric Association, an executive member of the Australian Association of Developmental Disability Medicine (AADDM) and executive member of Association of Doctors in Intellectual Disability (ADDintellectual disability).

Appendix 2

Article 25 UN Convention on the Rights of Persons with Disabilities

Article 25: Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.