



Australian Association of Developmental Disability Medicine Inc.

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*Secretary:* Dr Jane Law

5 February 2015

Community Affairs Reference Committee

Committee Secretary

Senate Standing Committees on Community Affairs

**Re: Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia**

The Australian Association of Developmental Disability Medicine (AADDM) is an organisation of medical practitioners who specialise or have an interest in the health of the over 300,000 Australian children, adolescents and adults with intellectual disability (ID). The key aim of the AADDM is to improve the health of children, adolescents and adults with intellectual and developmental disability.

*AADDM wishes to make a submission addressing Terms of Reference*

*c) the health and support pathways available to young people with complex needs.*

People with intellectual disability have poor health status. Overall they have very high rates of physical and mental health problems which are often not diagnosed or appropriately treated. Furthermore, their life expectancy is reduced by up to 20 years. They often have the added burden of socio-economic disadvantage and experience many barriers to receiving health services which directly impact their health and health care.

Children, adolescents and adults with ID experience higher rates of many treatable health conditions compared to the mainstream population. The most comprehensive study of this type finding 5.4 conditions per person; half of which were unrecognised or poorly treated.

There are many causes of this situation; communication barriers between patients and health professionals, complexity of diagnosis, lack of general and specialised skills in the health workforce, passive or active discrimination within the health systems and absence of tailored health promotion campaigns and research not focusing on people with intellectual disability.

People with intellectual disability are more likely to receive inappropriate and inadequate treatment, or be denied healthcare altogether. The Royal Australian College of Physicians recommends that multidisciplinary models of care should be established at the time of diagnosis of intellectual disability. These should be characterised by effective and sustained collaboration across sectors, health, disability, education and family and community services, and professionals.

*Specifically, in relation to the terms of reference, we note that:*

- **The existing pathways to health care do not, in general, meet the needs of young people and their families/carers**
- **Health care pathways must be developed that recognise**
  - The lifespan health and social consequences of having ID
  - The key points of transition, including from paediatric to adult health services, and the potential adverse impact on continuity of care
  - The poorer health outcomes for people with ID and the need to ensure improved preventative health care and diagnosis and management of existing health conditions starting during childhood and adolescence
  - Recent federal and state initiatives have not addressed inequities in health outcomes nor poorer experiences of health care services
  - The need for multidisciplinary teams that may include professionals outside the health system, such as education and schools
- **Models of health care should be consistent across place of residence and type of carer**
  - To maintain same high standard of health care no matter where the person is living
  - To enable continuity of care to be maintained whether the young person is living temporarily away from main residence/carers
  - Flexibility in models of care to accommodate variation in carers
  - Strategies to ensure effective communication between services/professionals especially where more than one carer is involved
- **Health outcomes should be measured for young people with ID**
  - Healthcare standards should be developed
  - Health outcomes should be measured
  - Progressive reduction in healthcare disparity should be demonstrated
- **Health and disability services should develop consistent approaches to health care interventions provided by the disability sector**
  - Staff in disability sector implementing healthcare intervention, eg tube feeding, administration of medication- should have suitable level of training
  - Health care needs should be documented in a consistent way across the disability sector, eg medication charts and interventions provided to be of same standard no matter where delivered.

Yours sincerely



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President of AADDM

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