

Inquiry into Dementia: Early diagnosis and Intervention

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Background

I am a consultant psychiatrist, subspecialising in psychiatry of old age and psychiatry of intellectual and developmental disabilities. I am Director of Mental Health at the Centre for Developmental Disability Health Victoria, Monash University where I conduct a Psychiatric Clinic for Adults with Down syndrome, many of whom have early onset dementia of Alzheimer's disease, as well as a Psychiatric Clinic for Older People with Intellectual Disabilities. I am conducting research into healthy ageing, assessment, management and service provision for people with intellectual disabilities and dementia in association with Professor Christine Bigby, Latrobe University, Professor Teresa Iacono, Latrobe University and Associate Professor Julian Trollor, University of New South Wales. I also work in a mainstream Cognition Dementia and Memory Service in Melbourne as well as consulting to psychogeriatric facilities. My specific area of expertise is in the diagnosis and management of dementia in people with intellectual disabilities. Clinical experience and research indicate that this is a population of high unmet need in terms of diagnosis, support and accommodation options.

This submission is

1. Identified in the submission from Cognition, Dementia and Memory Services (CDAMS) Victoria in relation to

Recommendation 7

Identify best practice in the assessment and diagnosis of dementia in CALD, ATSI and intellectual disability populations, making these models more widely available and better resourced.

2. Relates specifically to the population with intellectual disability and dementia
3. Endorses the CDAMS submission and situates the population with intellectual disabilities and dementia within that framework.

Early Diagnosis and Intervention for People with Intellectual Disabilities and Dementia

The population of people with intellectual disabilities and dementia may be subdivided into 2 major groups:

1. People with Down syndrome and early onset dementia of Alzheimer type
2. People with other intellectual disabilities and various dementias, with onset a decade earlier than the general population.

People with Down Syndrome and Early Onset Dementia of Alzheimer's Disease

It is an established fact that people with Down syndrome develop early onset dementia of the Alzheimer's disease, generally between 40 years and 60 years, with a peak in the early to mid 50s. Prevalence figures vary but a general rule of thumb is that 50% of people with Down syndrome will develop dementia by the mid 50s. An unpublished longitudinal study in Ireland indicates that up to 90% will ultimately develop dementia (Professor Mary McCarron, 2010, Trinity College, Dublin. Personal Communication). This eclipses the prevalence of dementia in the general population and occurs in middle age rather than in later age. No other population group has such high rates of early onset dementia.

People with Down syndrome comprise about 15% of the identified adult population with intellectual disabilities {Glasson, 2002 #5; Singer, 1997 #1776; Mantry, 2008 #1784}. People with Down syndrome are one of the largest disability groups, being greater than the population with autism, cerebral palsy or blindness/Deafness. Median life expectancy has increased from just 2 years in the late 60s, to 25 years during the 1980s to 50 years at the turn of the century. Average life expectancy of people with Down syndrome is approaching 60 years, with 75% surviving to age 50 years. This has resulted in an exponential increase in the numbers of middle aged adults with Down syndrome, who are now at exceedingly high risk for developing dementia.

People with Other Intellectual Disabilities and Dementia

The life expectancy of people with intellectual disabilities in general is now 60 years. When considering people with mild intellectual disabilities life expectancy is higher. When in good general health life expectancy is approaching that of the general population. {Patja, 2000 #1770}

Population based studies in the United Kingdom have consistently found that 1 in 5 people, aged 65 years plus, with intellectual disabilities – other than Down syndrome- have dementia {Cooper, 1997 #325; Strydom, 2007 #2722}. In addition there is a "hidden" population with mild-borderline intellectual disabilities, with poor general health, who are not in receipt of disability services, though they may receive a variety of other services {Emerson, 2011 #3718}. The risk for dementia in this hidden population is not known, but is predicted to be increased.

Article 25 of the United Nations Convention on the Rights of People with Disabilities {United Nations, #2861} requires signatory states to provide equitable access to equal quality health care but to also provide access to health care that is specific to the disability. This means that people with intellectual disabilities should have the same access to early diagnostic services as the general population. Access means more than receiving a service, but involves access to appropriate expertise within the service. Early onset Alzheimer's disease is a specific consequence of Down syndrome, related to triplication of chromosome 21 and the over-expression of the amyloid precursor protein. It could be argued that specific services should be provided for assessment of dementia in people with Down syndrome. However to date federally funded health, ageing and dementia programs have not identified this significant minority population in the same way that other diverse populations, with specific needs, have been identified for special consideration such as CALD, ATSI but also gay, lesbian and transgender people and other groups. It is disappointing and puzzling that the significant unmet health needs of the population with intellectual disabilities is not recognised and addressed. To include the population with intellectual disabilities amongst diverse populations identified for special consideration would increase general awareness, especially amongst professionals and service providers, increase research efforts and development of the evidence base and promote service innovation.

Recommendation 1

Older with intellectual disabilities are a rapidly increasing minority population who are at high, to exceptionally high, risk of dementia in comparison with the general population, with earlier onset. All federally funded programs relating to health, ageing and dementia should include the population with intellectual disabilities for special consideration in the same way that other significant minorities such as CALD, ATSI, and other diverse and minority groups are considered. This would be in line with the requirements of Article 25 of the UN Convention on the Rights of People with Disabilities.

Early Diagnosis of Dementia in People with Intellectual Disability

Diagnosis of dementia in people with intellectual disabilities is a complex clinical challenge for multiple reasons {Torr, 2009 #3463}:

1. Pre-existing lifelong cognitive and functional impairments ranging from borderline/mild to moderate to severe profound intellectual disability
2. Standard assessment instruments are not valid for use in this population. Adapted diagnostic instruments lack population norms. Hence individual baseline assessments are required to establish cognitive decline.
3. High rates of comorbid health condition and mental health conditions, many unidentified, and adverse effects of polypharmacy, may be the cause of functional decline which is misdiagnosed as dementia.
4. Lack of training of medical specialists.
5. Small distributed population results in limited experience and development of expertise in medical specialists.

People with Down syndrome have high rates of co-morbid health and mental health conditions and high rates, and early onset, of other age related disorders, in addition to dementia, such musculoskeletal disorders including osteoarthritis, osteoporosis, falls and fractures, resulting in additional disability. By the age of 50 years, more than 60% will have vision impairment and more than 60% will have hearing impairment. Death rates from chest infections and seizures escalates in middle age. {Torr, 2010 #3094} My observations are that

it is often assumed that a middle aged person with Down syndrome and behaviour or functional change has dementia when in fact the person has a different or additional treatable condition. Diagnosis requires careful assessment not presumption. This is a time consuming process that may require multiple assessments over time, and management of a range of disorders. The compartmentalised nature of the health system makes such assessments difficult to coordinate and complete.

People with other intellectual disabilities are also frequently misdiagnosed with dementia when they have other disorders. In a 30 bed psychogeriatric facility, 4 residents are under the age of 65 years, with mental illnesses such as schizophrenia and bipolar disorder, who have been incorrectly diagnosed with dementia.

Recommendation 2

Accreditation of health professional training should require training in the assessment and management of people with intellectual disabilities. General practitioners need to be upskilled to identify who needs specialist assessment. Geriatricians, neurologists and psychiatrists require specific training in the assessment of dementia in people with intellectual disabilities and the differentiating other conditions from dementia.

Recommendation 3

Development of quality education and training modules in the assessment and diagnosis of dementia in people with intellectual disabilities.

Recommendation 4

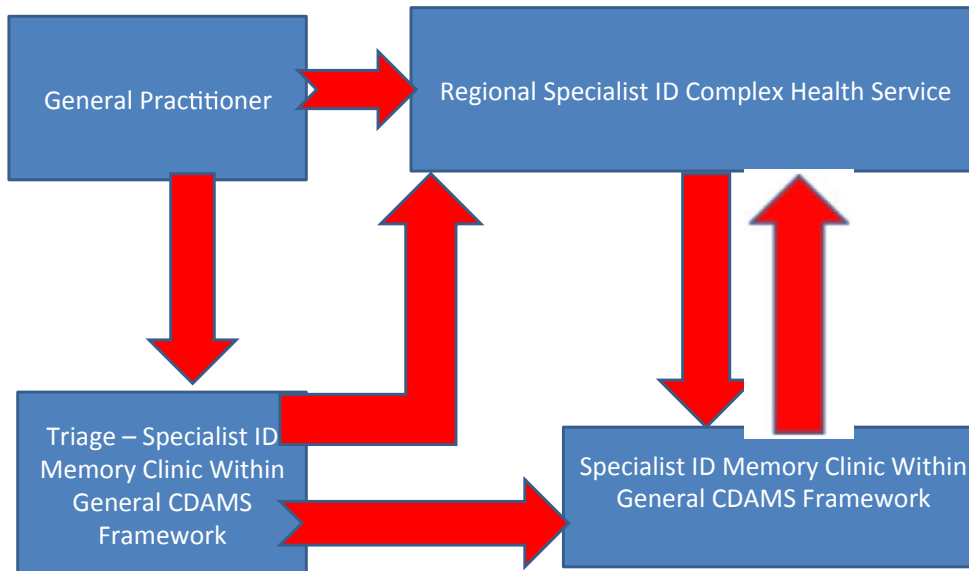
Establishment of early dementia assessment services with specific expertise in the assessment of people with intellectual disabilities. This would allow the development of focused expertise, opportunities for training and to model practice.

Pathways to Care

Early expert assessment of dementia will not happen if a person is not referred for assessment. Generally the nature of the problem must be identified for the person to be referred to the appropriate diagnostic service. However, for example, in a person with aged, say 45 years with Down syndrome who presents to their general practitioner with behaviour and functional change could have a myriad of disorders. So where does the GP refer the person for assessment.

Research conducted by myself, Professors Bigby and Iacono and Dr Rachel Carling-Jenkins has identified issues regarding the pathway to care from identification of an emerging problem by families and carers, to identification of the nature of the problem by general practitioners and then refusal of mainstream services to provide assessment. The Psychiatric Clinic for Adults with Down syndrome at CDDHV is a single practitioner, office based, limited consultation only service with no capacity for follow up care. But what this clinic does provide is assessment regardless of the nature of the problem. That is a ball park diagnosis is not required to get an assessment. A GP does not need to work out if the person needs to see a physician, a psychiatrist, a psychologist for behaviour support, a neurologist, old age psychiatrist or geriatrician for a dementia assessment. We found that when families and carers were not aware of the direct pathway to the clinic, they were given the run around before finding out about the clinic by contacting the Down syndrome association. We have proposed the following pathway:
{Torr, 2010 #3878}

Proposed Pathways



This framework envisages multidisciplinary specialist intellectual disability health services, that are being piloted in NSW, and proposed in the health and hospital reforms. This would allow for people with medical, general physical, psychiatric and behaviour disorders who are referred to a memory clinic and assessed as not having or not likely to have a dementia to be diverted at triage or after assessment to the specialist intellectual health service and people with dementia referred to the health service to be referred to the memory clinic. People with dementia and a range of comorbid disorders could be assessed in both services. Subspecialist intellectual disability memory service within the overall memory clinic services would provide support in assessment or direct assessment or co-assessment.

Recommendation 5

Development of specialist health, mental health and memory services for people with intellectual disabilities and clarification of pathways to care.

Interventions

Early diagnosis is just the beginning. A model of assessment, psychoeducation and linkage with support services as CDAMS clinics in Victoria needs to be provided for people with intellectual disabilities, families, support workers and disability service managers.

Social networks and supports for people with Down syndrome and other intellectual disabilities are atypical. In particular people with Down syndrome and emerging dementia generally live in the family home by their elderly parent/s, or care is shared amongst siblings, or they live in group homes. Increasingly people with Down syndrome and other disabilities are living independently in the community or in other types of accommodation. Often referral of a person with Down syndrome, aged around 50 years, with a clear cut diagnosis of dementia of Alzheimer type, living with family, is refused by the local aged care assessment service because 1. The person is not 65 years 2. The person has a disability 3. The person is not 65 years and has a disability and therefore cannot be placed in an aged care facility even

though yes they have a dementia and yes even though placement is not what is being request but access to a community aged care package or an EACH-D package. These are not requests for packages for people living in a group home provided by a disability service provider.

To give one example. A 48 year old woman with Down syndrome, early onset dementia of Alzheimer's disease, who has lived all her life with her parents from a CALD background was refused assessment for a community aged care package because she had Down syndrome. Is this not a fundamentally discriminatory act?

It is my understanding that certain groups such as Aboriginal and Torres Strait Islanders and people with early onset dementias do not have to meet the 65 years rule. Has the right action to ensure that young people with disabilities are not accommodated for life in an aged care facility resulted in people intellectual disabilities with a serious age related, but early onset dementia, being denied access to funding and services? The responses to requests for assessment by ACAS varies from region to region. Clearly policy is not clear and is not consistently interpreted and applied.

Furthermore people living in group homes are seriously disadvantaged and refused access to a range of allied health services that would be provided to someone with dementia living at home. Have group homes been confused with aged care facilities which are required to provide these services? Group homes provide accommodation support, not health care. A man with Down syndrome and early onset dementia living in a group home run by an NGO was denied access to allied health services because he lived in a group home. Is that not discriminatory? Does the provision of allied health care such as physiotherapy fall within the CSTDA framework?? If so how is this accessed? Furthermore aged care facilities generally have visiting general practitioners. Some with an intellectual disability who refuses the leave the house or is in a wheelchair and cannot access transport, cannot access a general practitioner.

The failure to provide adequate support within family home, or group homes can only result in premature placement in an aged care facility. Access to ACAS assessments to move someone from an inpatient bed into a nursing home seems rather speedy compared with trying to access a package within the community.

Given the multitude of experiences of individual and reasons given for not providing a service it is difficult to distil the key issues. Suffice it to say that the situation is simply not acceptable, policy is unclear and discrimination common, even if the result of being misinformed. I have been informed by federal ministers for health or for ageing or for mental health that people with intellectual disabilities can access the range of federal initiatives that anyone else can access. My experience is otherwise. I would welcome the opportunity to present to the committee on these issues.

Recommendation 6

Clarification of policy regarding access to community aged care packages and allied health services and aged health services for people with intellectual disabilities with aged related and early onset age related disorders such as dementia.

There is a limited evidence base about how to best support someone with intellectual disability and dementia. Families and support workers need education and support. Service managers also need training. I have recently had to issue a medical certificate for a person with Down syndrome, who lives in a group home, and who has early onset dementia stating that they were not fit to continue work, due to loss of ability to do the work and extreme

distress at work, so that the person could retire and access a day program tailored to their needs.

Recommendation 7

Development of evidence based interventions and development of educational materials and training programs for families, support workers and disability service providers and other care and support providers.