SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE
INQUIRY INTO THE FUNDING AND OPERATION OF THE
COMMONWEALTH STATE/TERRITORY DISABILITY AGREEMENT

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TERMS of REFERENCE

This submission is in relation to the following terms of reference

(b) the appropriateness or otherwise of current Commonwealth/State/Territory joint funding arrangements, including an analysis of levels of unmet needs and, in particular, the unmet need for accommodation services and support;
(c) an examination of the ageing/disability interface with respect to health, aged care and other services, including the problems of jurisdictional overlap and inefficiency;

with an emphasis on the needs of older people with intellectual disabilities.

BACKGROUND

I am a psychiatrist who has specialized in the psychiatry of old age and the psychiatry of intellectual disability. I conduct a psychiatric clinic for older people with intellectual disability and a clinic for people with Down syndrome and Alzheimer's disease at the Centre for Developmental Disability Health Victoria, Monash Univeristy. I also work in a mainstream Cognition Dementia and Memory Service St Vincent's Health Service Melbourne as well as for the Aged Persons' Mental Health Service, Melbourne Health. I draw from my experience in these clinical settings and my discussions with families and disability workers to highlight issues in providing care to older people with intellectual disabilities.

SUGGESTED READING

- http://aging.state.ny.us/explore/project2015/report02/mental_retardation.pdf

- Wilkinson, H. and M. P. Janicki (2002). "The Edinburgh Principles with accompanying guidelines and recommendations." Journal of Intellectual Disability Research 46(3): 279-284.

RECOMMENDATIONS

- ***Rational planning for this small, but important and rapidly increasingly population requires detailed and accurate demographic data.***

- ***The needs of special subpopulations such as older adults with Down syndrome and Alzheimer's disease need to be identified to enable planning for the appropriate provision of services.***

- ***Greater resourcing will be needed to meet the needs of this rapidly increasing population.***

- ***Older people with ID living in disability services accommodation should be offered retirement options.***

- ***Older people with ID should be afforded the same opportunities to age in place as any other older person.***

- ***Older people with ID or other lifelong disabilities should be afforded the same services and support as anyone else in the community who is ageing and is affected by age related issues.***

- ***This should be regardless of whether or not they are already in receipt of CSTDA services. Older adults living in community group homes should have access to the same social and health care supports as any other adult with age related issues living at home alone or with family carers.***

- ***These services and supports need to be accessible to older people with ID or other life long disabilities who may be less than 65 years of age but are presenting with premature age related problems. For example middle aged people with Down syndrome and Alzheimer's disease.***

- ***In general older adults with ID should not be accommodated in aged care residential facilities unless they have as specific age related issue. This is in essence no different to accommodating younger people with ABI in aged care facilities. Older people with ID living with ageing parents need to be provided with timely disability accommodation when parents are no longer able to care for them.***

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- ***Resourcing of the addition care needs associated with age related issues should be met from the aged care budget rather than from the CSTDA budget.***

- ***Clarification of state and commonwealth responsibilities regarding accommodation, care and other services for people with intellectual disability and dementia or other age related problems.***

- ***Explicit requirement and accountability of government funded aged care services to provide services to people with intellectual disability and dementia.***

- ***Research into appropriate person centred and equitable service provision for people with intellectual disability and dementia***

- ***Examination of how ageing in place can be facilitated within community residential units and other settings.***

- ***Training of disability care workers and families in the care of people with intellectual disability and dementia.***

DEMOGRAPHICS

The life expectancy of people with intellectual disabilities increased dramatically during the 20th century from about 20 years in the 1930s [1] to about 60 years. Nonetheless this is close to 20 years less than for the general population.

These findings could account for the surprisingly small but increasing number of older people with intellectual disabilities in Australia. A 1995 study by Ashman et al [2] found only 446 people with intellectual disabilities aged 55 + years in Western Australia and Queensland. In 2000 there were an estimated 1348 people in Victoria with an intellectual disability aged 55 years and over. This number is projected to increase by 14% by 2005 and by 55% by 2020 [3].
Data from the Australian Institute of Health and Welfare (AIHW) Disability Cubes indicates a small national population of older people with intellectual disabilities in receipt of Commonwealth State Disability Agreement services [4]. This is surely an underestimate of older people with intellectual disability within Australia as only those in receipt of a CSDA service have been counted.

Age	Female	Male	Not Stated	**Total**
▼ **40-49 years**	4,534	3,575	41	**8,150**
▼ **50-59 years**	2,418	1,884	28	**4,330**
▼ **60 years +**	934	812	6	**1,752**
Total	7886	6271	75	**14232**

Table1. Australians with Intellectual Disability in Receipt of CSDA Service 2002 [4]

Age	**Total**
40-49 years	11,474
50-59 years	6,400
60-64 years	1,341
65 years and over	1,342
Total	20557

Table 2. Australians with Intellectual Disability in Receipt of CSDA Service 2003-4 [5]

DEMAND FOR SERVICES AND SERVICE PROVISION

AIHW data from Table 1 and Table 2 shows a rapid increase in older people in receipt of CSDA services from 14232 in 2002 to 20557 in 2003-4. This is an increase of 44%. Clearly such a dramatic increase cannot be accounted for by people inevitably moving into older age brackets. These figures only include people with intellectual disabilities who are actually in receipt of CSTDA services. Hence there has been a rapid increase in the demand for CSTDA services by older people with ID. Was such an increase expected? What strain has this put upon state disability resources? How well are needs being met? What are the unmet needs? Can provision of services be sustainable with current funding arrangements?

ACCOMMODATION and SOCIAL CARE

Ashman and colleagues [2] found that 18% of identified people with intellectual disability over the age of 55 years in Western Australia and Queensland lived in nursing homes. The study also found that older people with intellectual disabilities had little say in decisions about their accommodation. My professional experience of working in a community aged psychiatry assessment team indicates older people with intellectual disability may be placed into nursing homes when their family carers can no longer care for them, irrespective of whether they have an age related disorder or not. This is echoed by the experience in the United States where substantial numbers of healthy older people with intellectual disabilities are placed inappropriately nursing homes rather than in accommodation provided by disability services [6].

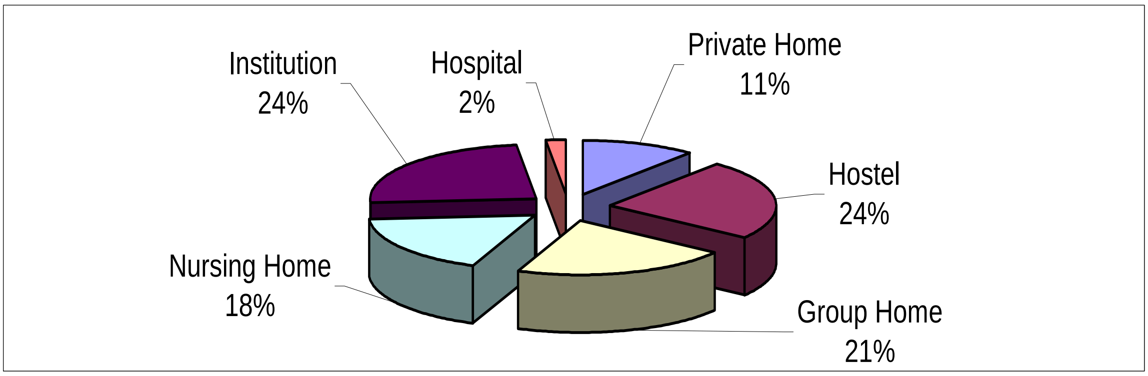

Figure1. Residential Circumstances Of Older (55+) Australians with Intellectual Disability. Data from [2]

It is not an uncommon scenario for older people with ID to to seek services for the first time when their ageing parents can no longer provide care through their own ageing, illness or death. Anecdotally this seems to be a particular problem in rural areas where people with ID have been supported by family and community rather than specific CSTDA services. My question is do we know how many older adults with ID and ageing parents are not being accounted for in the CSTDA data.

I am particularly concerned with the needs of older people with Down syndrome who are at a particular risk of developing Alzheimer’s disease in middle age. Also parents of people with Down syndrome tend to be older and the age related issues of parents and adult child with DS often coincide. It is not uncommon to encounter a mother and adult child with DS both presenting with Alzheimer’s disease.

Another issue is the provision of retirement options. It is standard policy that young adults with ID complete school at the age of 18 and undertake adult options such as day program, work or TAFE. No such parallel for the “normal” transition from work to retirement is in practice.

HEALTH AND AGEING IN INTELLECTUAL DISABILITY

Comorbid conditions related to the aetiology of the ID or aquired disorders are often chronic, unrecognized and untreated resulting in poorer health outcomes and earlier onset of age related conditions. In Australia the standardized mortality rate for people with ID is 4.9 [7]. A London study has found that people with ID are 58 times more likely to die before the age of 50 than general population [8]. Conditions such as Down syndrome are associated with a range of medical disorders, premature ageing and early onset Alzheimers disease. The onset of dementia in people with ID in general is about a decade earlier than the general population. The demarcation line of 65 years as defining elderly for purposes of service provision needs reviewing with respect to people with ID.

Deinstitutionalisation of care of people with intellectual disabilities separated social care from health care. The move to a social model of care has ignored the varied and often complex health needs of people with intellectual disabilities. State disability services provide social care and the expectation is that mainstream health services will meet the health care needs of people with intellectual disabilities. However state disability services do have a role to play in health care of people with intellectual disabilities. As the providers of supported accommodation and general care disability service providers have a role to play in managing lifestyle risk factors. Disability workers are expected to be able to identify when someone needs to access a health service, arrange access, coordinate care, attend appointments, manage health information and to follow through on recommendations. All of this is required of people who are not health professionals. Many, but certainly not all, disability workers have had minimal training. In Victoria mental retardation nurses were abolished more than a decade ago.

Australian doctors are not well trained in providing medical care to people with intellectual disabilities. General practitioners [9] and psychiatrists [10] report not being adequately trained to meet the general health and mental health needs of people with intellectual disabilities. Efforts are being made to address this with improvements in undergraduate and postgraduate training. There are no medicare items that remunerate doctors for the additional time and complexity of assessing and managing health problems of a person with intellectual disability.

DEMENTIA IN PEOPLE WITH INTELLECTUAL DISABILITIES

An epidemiological study by Cooper [11] found high rates of dementia (21%) in elderly people (>65 years) with intellectual disability not due to Down syndrome. This was about 4 times the rate of dementia expected in the age-matched general population. There are many possible reasons for this high rate of dementia including low IQ, low educational attainment, poor control of vascular risk factors, the neurotoxic effects of epilepsy, the adverse effects of lifelong medication in particular the hypotensive effects of many psychotropics, accidental and self injurious head injury and progression of the underlying disorder.

In addition people with Down Syndrome (trisomy 21) are at particular risk of developing Alzheimer's disease in the 5th and 6th decade of life [12-14]. This is thought to be due to the presence of 3 copies of the amyloid precursor protein (APP) genes, one on each chromosome 21, resulting in abnormally high amyloid production and precocious deposition in the brain precipitating the amyloid cascade that leads to the development of Alzheimer's disease [13, 14]. Post mortem studies have established that all people with Down syndrome have the neuropathological brain changes consistent with Alzheimer's disease by the age of 40 years [15]. However the average age of clinical diagnosis is about 50 years [12]. Around 30% of people with Down syndrome are diagnosed as having Alzheimer's disease in their 40s, increasing to 50% being diagnosed in their 50s [16].

As recently as 40 years ago only 50% of infants with Down syndrome survived infancy. The median life expectancy of people with Down syndrome increased dramatically from 25 years in 1983 to 49 years in 1997 [17]. The number of people with Down syndrome increased four fold during the 1980s. I have been unable to obtain figures from Disability Services as to how many older people with Down syndrome live in Victoria. Without such figures how can rational planning for services to meet the needs of this group be met? With regard to dementia assessment services should all dementia assessment services be upskilled in assessment and management of people with Down syndrome and Alzheimer's disease? Or should few geographically selected services be targeted or would a statewide service with deep expertise be developed?

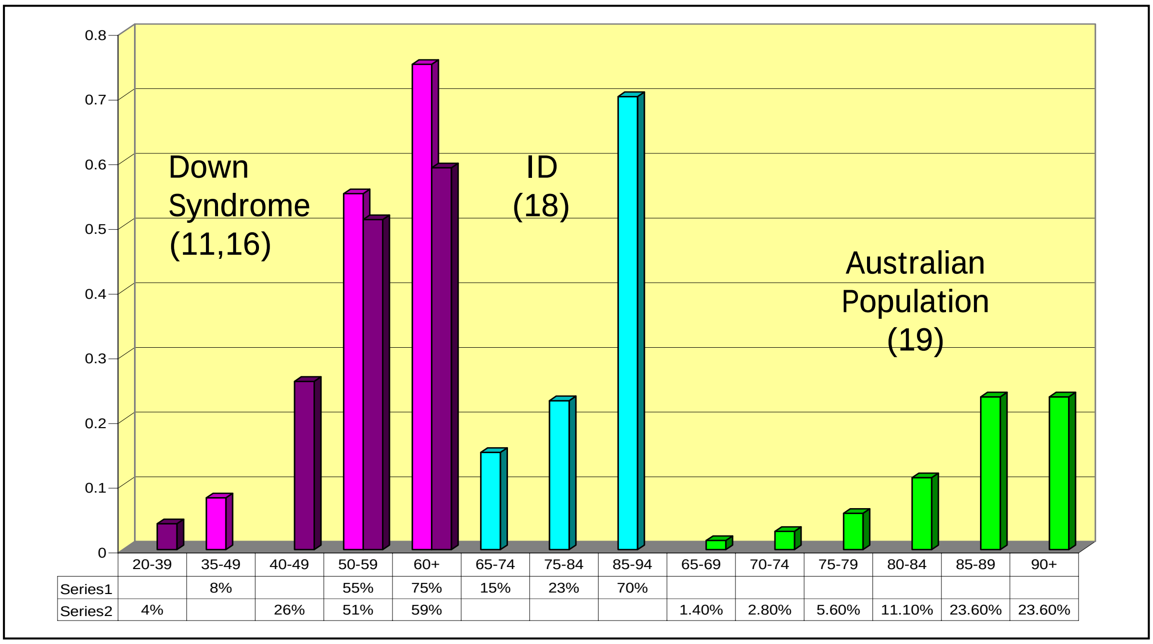

Figure 2. Prevalence of dementia in people with Down syndrome, intellectual disability and the general population. Data from [11, 16, 18, 19]

SERVICES AND CARE OF PEOPLE WITH INTELLECTUAL DISABILITY AND DEMENTIA

A 50 year old with Down syndrome, recurrent chest infections due to lowered immunity and aspiration, depression and Alzheimer's disease living at home with elderly parents or in a community group home needs to access a range of social, health, mental health and aged care services provided at by non government organizations, local government social services, state disability services, private general practice, state health and mental health services, and Commonwealth funded aged care services. The potential for service demarcation disputes is played out daily in the lives of older people with ID and range of comorbid problems.

Examples include Aged Care Assessment Services refusing to assess a 48 year old lady with Down syndrome and Alzheimer's disease living in a community group home on the grounds that she is only 48 years old, has an intellectual disability and besides it's not appropriate to place a young person in a nursing home. This not uncommon scenario illustrates a number of issues. Intake clinicians may not have the training, experience or expertise to tease out the issues. Someone with Alzheimer's disease, regardless of age is entitled to an aged care assessment with a view to accessing services or placement in an aged care residential facility. Alzheimer's disease is a terminal condition. There comes a time when end of life care in a nursing home is an appropriate option. A young person with an acquired brain injury or a severe physical or intellectual disability has a more or less static condition and nursing home care is not appropriate. Often the issues are confused. What needs to be clarified is that the referral to ACAS is for an age related problem, not because the person has an intellectual or other disability.

The same 48 year old person with Down syndrome lives in a group home where no staff are present during the day. They may need to attend day placement each weekday and may need to attend when ill as additional staff must be employed if the person is to stay at home. Extra staff are also required to accompany the person to medical and other health related appointments.

As the general care needs increase the current compliment of direct care staff have less time to devote to the other residents of the house. This may lead to reduced community access especially on the weekends. Currently funding for additional staff comes from the disability budget. I am not aware of aged community care packages providing for additional services and supports for a person with Down syndrome and dementia living in a community group home. I have met many devoted direct care staff who do their utmost to meet the increased care needs of the individual whilst maintaining social care of the other residents. In Victoria a number of people with Down syndrome and Alzheimer's disease in their early 50s have moved to community group homes specifically established for older people with ID. However this has not been an option for all. This may lead to earlier placement in a nursing home.

It is an established principle that people with disabilities should be afforded the same opportunities as the general community. I refer the committee to the Edinburgh Principles with accompanying guidelines and recommendations. These principles refer to the design and provision of services to people with ID affected by dementia. These principles are readily applied to people with ID who are ageing or affected by age related disorders in general. Someone with Down syndrome and Alzheimer's disease should be afforded the same opportunities to age in place as an 80 year old with Alzheimer's disease in the general population. The elderly that I see in mainstream clinical settings can access a range of support services to maintain them in their own homes and to delay placement in an aged care facility. People with intellectual disability affected by dementia who live in disability accommodation are not afforded the same support. Whether this is due to actual policy or simply because it is established practice is not clear. Nonetheless it is discriminatory. It also makes state disability services responsible for meeting the additional needs of ageing with a disability. From the Commonwealth's point of view is it not more economic to provide addition support for older people with ID and additional age related conditions to remain in community group homes rather than premature placement in aged care facilities?

PREVENTION *of* DEMENTIA IN PEOPLE WITH INTELLECTUAL DISABILITIES

Prevention of dementia in people with intellectual disability requires general preventive health care and attention to lifestyle factors.

> "Poor access to general medical care means later diagnosis and treatment and less preventive care and management of vascular risk factors. Lifestyle factors such as nutrition, obesity, exercise and smoking may all contribute to additional risk. The general risk factors for dementia of low IQ and poor education also apply. Epilepsy is extremely common in people with intellectual disability [19]. Do the effects of life long epilepsy and anticonvulsants contribute to the risk for dementia? Head injury is a risk factor for dementia and head injury in intellectual disability may be the cause of the disability or a consequence of falls, accidents assaults and self injury. What about the hypotensive effects of many psychotropics? Are there syndrome specific risk factors and progression of underlying disorders? The investigation of risk factors for dementia in people with intellectual disability is fertile ground for research."[20]

TREATMENT of DEMENTIA

Currently people with intellectual disabilities and Alzheimer's disease have access to cholinesterase inhibitors under the pharmaceutical benefits scheme. This was not always the case and the criteria for authority prescription discriminated against people with intellectual disability and other issues relating to language, education, cultural background, sensory impairments etc. Criteria for access to future medications should also be modified so that different groups are not discriminated.

People with intellectual disability need improved access to aged psychiatry services for treatment and management of behavioural and psychological symptoms of dementia.

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