National Framework for Action on Dementia National Stakeholder Feedback

Submission From

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Thankyou for the opportunity to comment on the National Framework for Action on Dementia 2005 Consultation Paper. My comments are focused on the needs of people with intellectual disability and dementia. I am encouraged by the identification of need to address issues in the diagnosis of dementia and the provision of appropriate services to people with intellectual disability.

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.

RECOMMENDATIONS

Demographics

1. Scoping of the demographics and service needs of people with intellectual disability and dementia.

Prevention, Assessment and Treatment

2. Research into the prevention, assessment and management of dementia in people with intellectual disability.
3. Funding for the development and implementation of protocols for the assessment and management of people with intellectual disability and dementia.
4. Funding for the training of specialists and registrars in the assessment, diagnosis and management of people with intellectual disability and dementia.
5. Funding for the training of other health professionals in aged care services in the assessment and care of people with intellectual disability and dementia.

Service Provision and Care

6. Clarification of state and commonwealth responsibilities regarding accommodation, care and other services for people with intellectual disability and dementia.
7. Older people with intellectual disability who do not have significant aged related physical and/or medical morbidity should not be accommodated in nursing homes.
8. Explicit requirement and accountability of government funded aged care services to provide services to people with intellectual disability and dementia.
9. Research into appropriate person centred and equitable service provision for people with intellectual disability and dementia
10. Examination of how ageing in place can be facilitated within community residential units and other settings.
11. Training of disability care workers and families in the care of people with intellectual disability and dementia.
12. Development of literature and other resources for professionals, service providers, families, carers, peers of people with intellectual disabilities and dementia.

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DEMOGRAPHICS

The absolute number of older people with intellectual disabilities in Victoria is small.
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 [Bigby, 2001 #686]. Data from the Australian Institute of Health and Welfare Disability Cubes indicates a small national population of older people with intellectual disabilities in receipt of Commonwealth State Disability Agreement services [1]. 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. Ashman and colleagues [2] found that 185 of identified people with intellectual disability over the age of 55 years in Western Australia and Queensland lived in nursing homes, that is 18% of the identified population. 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 [3].

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 [1]

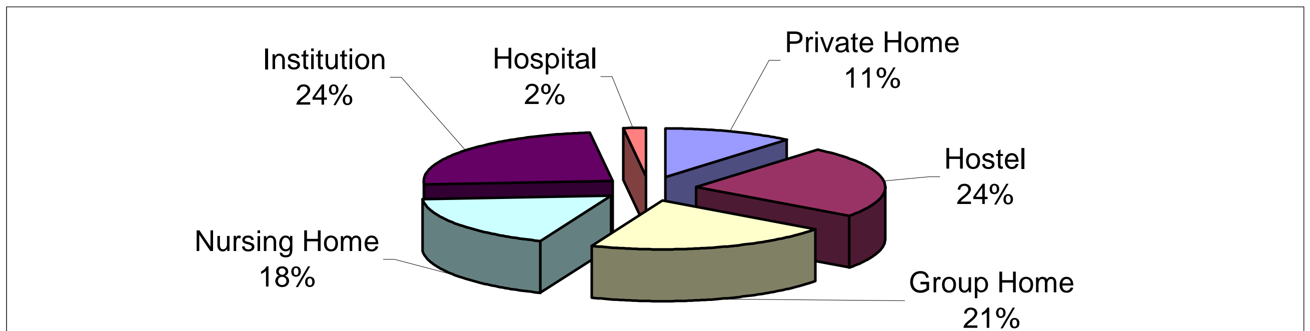


Figure1. Residential Circumstances Of Older (55+) Australians with Intellectual Disability. Data from [2]

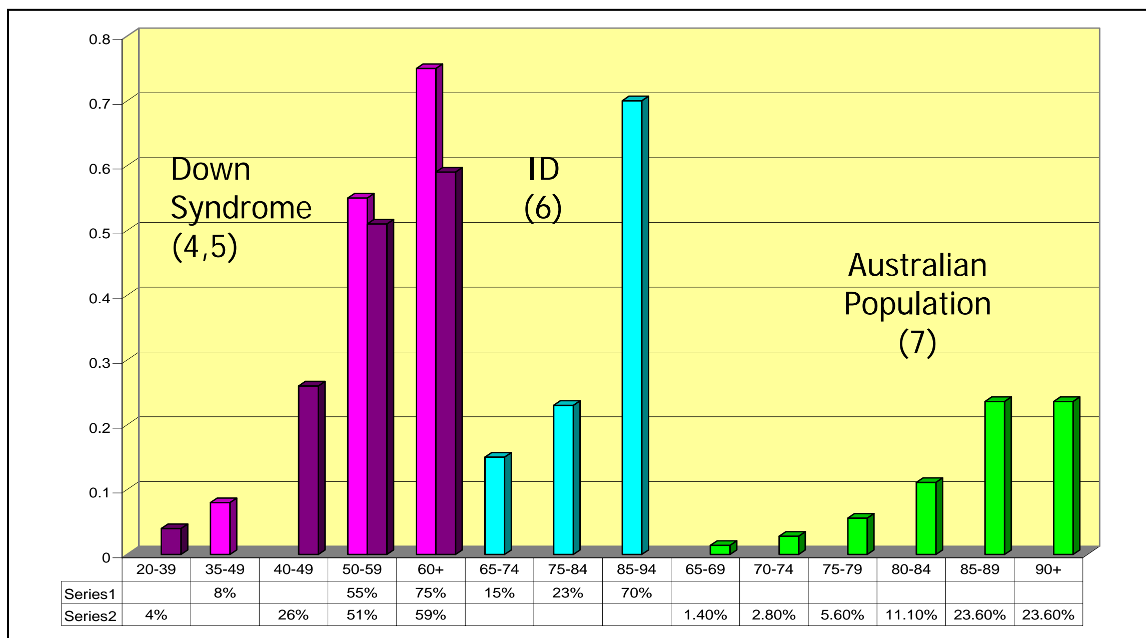
- ***Rational planning for this small, but important and rapidly increasingly population requires valid demographic data.***

- ***Older people with intellectual disability who do not have significant age related morbidity should not be accommodated in nursing homes.***

DEMENTIA IN PEOPLE WITH INTELLECTUAL DISABILITIES

An epidemiological study by Cooper [Cooper, 1997 #325] 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 [Holland, 1998 #536]. 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 [Isacson, 2002 #633; Rumble, 1989 #388]. 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 40years [Schweber, 1989 #382]. However the average age of clinical diagnosis is about 50 years [Holland, 1998 #536]. 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 [Lai, 1989 #520].



	20-39	35-49	40-49	50-59	60+	65-74	75-84	85-94	65-69	70-74	75-79	80-84	85-89	90+
Series1		8%		55%	75%	15%	23%	70%						
Series2	4%		26%	51%	59%				1.40%	2.80%	5.60%	11.10%	23.60%	23.60%

Figure 2. Prevalence of dementia in people with Down syndrome, intellectual disability and the general population. Data from [4-7]

- ***Rates of dementia are high in people with intellectual disability***

ASSESSMENT of DEMENTIA IN PEOPLE WITH INTELLECTUAL DISABILITY

Diagnosis of dementia in a person with intellectual disability is a clinical challenge involving a complex assessment process that establishes an individual baseline, demonstrates functional decline consistent with a specific type of dementia (most commonly Alzheimer's disease or vascular dementia) that is not attributable to other disorders even if these disorders are present. Cooper [8] has found high rates of physical illness in elderly people with intellectual disability and dementia, in particular urinary incontinence, immobility, hearing impairment, arthritis, hypertension, other cardiovascular disorders, respiratory disorders and cerebrovascular disease. Differentiation of functional decline due to physical illness from decline due to dementia can be extremely difficult.

Establishing baseline functioning and tracking decline is often hampered by the lack of useful documentation, multiple care givers who have known the person for a short period time. Protocols for documenting functioning over time, especially for people with Down syndrome need to be established to enable early and accurate diagnosis of dementia.

The fact that many if not most but certainly not all people with Down syndrome develop clinically evident Alzheimer's disease in middle age could lead to presumptive but incorrect diagnosis of Alzheimer's disease in people with Down syndrome. I am aware of people with Down syndrome as young as 30 years being diagnosed with Alzheimer's disease when they actually have an adjustment disorder or depression. There is also a tendency to query dementia in people with intellectual disability not due to Down syndrome who are in their 50s as having dementia when behaviour change occurs.

Standard screening tests such as the Mini Mental State Examination (MMSE) are not validated for use with people with ID as well as having substantial floor effects. In response there has been a proliferation of assessment tools for screening and diagnosing dementia in people with intellectual disability. International research groups are developing their own instruments and as yet there is no standardized approach. However the psychometric properties of these instruments have not been extensively examined and many are not readily available. Nonetheless such instruments have value as screening instruments as well as some utility in tracking the progression of functional decline.

Further research is also required for the development of valid and reliable neuropsychological assessments.

- ***Additional training of dementia specialists is required for the assessment of dementia in people with intellectual disability.***
- ***Assessment protocols need to be developed to assist clinicians in assessing and diagnosing dementia in people with intellectual disability.***

- ***Protocols for documenting functioning and decline in functioning for people with intellectual disability, especially those with Down syndrome need to be developed***
- ***Identification of accessible, user friendly, reliable and valid screening tools are required to identify people who need a dementia assessment***

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."[9]

In addition people with Down syndrome should have access to preventive treatments for Alzheimer's disease as these become available in future.

TREATMENT

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.

- ***Criteria for medications to treat and manage dementia need to take into account the effects of intellectual disability.***

STATE, NATIONAL AND INTERNATIONAL POLICIES AND PHILOSOPHIES REGARDING SERVICE PROVISION FOR PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA

Victorian Government Policy Context

The *State Disability Plan 2002-2012* outlines a vision of a more inclusive community where people with disabilities have the same rights, opportunities and responsibilities as all other citizens in Victoria [10]. In addition to these broad policies the Intellectual Disability Persons Services Act [11] enshrines the right of people with intellectual disability to the same rights of access to government funded services as the general population and requires services to adapt to the needs of people with intellectual disabilities.

National Policy

Federal Disability Discrimination Act [12]. Human Rights and Opportunity Commission.

International Perspectives

In 2000, The World Health Organization (WHO), International Association for the Scientific Study of Intellectual Disability (IASSID) and Inclusion International published a report entitled "Healthy Ageing - Adults with Intellectual Disabilities: Ageing and Social Policy" [13]. Recommendations of particular relevance to the submission are:

> 7d. Policies should be implemented to diagnose Alzheimer's dementia accurately in the general population with the inclusion of individuals with developmental disabilities and employment of suitable care management practices.
> 7e. In line with the overall policy of inclusion in mainstream services …., consideration should be given to the inclusion of Down syndrome individuals with dementia in services for people with dementia in the wider population.

The Edinburgh Principles [14] developed by a panel of experts in 2001 outlines the rights and needs of people with intellectual disability and dementia as well as defining service practices which will enhance supports available to them.

1. Adopt an operational philosophy that promotes the utmost quality of life of people with ID affected by dementia, and whenever possible, base services and support practices on a person-centred approach.
2. Affirm that individual strengths, capabilities, skills and wishes should be the overriding consideration in any decision-making for and by people with ID affected by dementia
3. Involve the individual, her or his family, and other close supports in all phases of assessment and services planning and provision for the person with an ID affected by dementia

4. Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs and support the healthy ageing of people with ID affected by dementia
5. Plan and provide supports and services which optimize remaining in the chosen home and community of adults with ID affected by dementia
6. Ensure that people with ID affected by dementia have the same access to appropriate services and supports afforded to other people in the general population affected by dementia
7. Ensure that generic, cooperative and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future need of adults with ID affected by dementia.

TRANSLATION OF POLICY INTO OUTCOMES FOR PEOPLE WITH INTELLECTUAL DISABILITIES AND DEMENTIA

Understanding and implementation of state, national and international policy statements and legislation outside the disability field is patchy. Although there are self advocacy movements, in general people with intellectual disabilities cannot advocate for themselves and depend on others to ensure that their rights are upheld. Health professionals receive little if any training in intellectual disability during undergraduate and postgraduate training. The result is inadvertent discrimination against people with disabilities and lack of confidence and ability of health professionals in providing appropriate assessment, management and care services. Anecdotal evidence indicates the intake workers in services such as aged care assessment services do not understand that people with Down syndrome commonly have Alzheimer's disease in their 5th and 6th decades. Assessment has been denied to some people with Down syndrome and Alzheimer's disease on the grounds that the person is not 65 years old. Carers have also be informed that CDAMS clinics do not assessment people with intellectual disability.

The small absolute numbers of older people with intellectual disability compounds the challenge in providing an accessible, competent and informed services to people with intellectual disability and dementia as each service and each clinician will only be assessing small numbers of people with intellectual disability, limiting experience and the development of expertise. Surveys of Victorian and Queensland Psychiatrist and Psychiatry trainees have demonstrated that psychiatrists and psychiatry trainees have received little if any training in assessing and managing people with intellectual disabilities, have limited clinical experience, lack confidence, recognize the need for specialist services but many would prefer not to see people with ID themselves[15-17]. The expectation that Royal Australian and New Zealand College of Psychiatrists (RANZCP) trainees will develop skills in this area will appear in the training regulations for the first time in 2003 [18]. Intellectual disability does not appear on the curricula for other speciality training.

The Centre for Developmental Disability Health Victoria operates the only psychiatric clinics specifically for older people with intellectual disabilities and for People with Down syndrome and Alzheimer's disease in Australia. The clinic was established by Dr Jennifer Torr who is the only psychiatrist in Australia with training in both old age psychiatry and the psychiatry of intellectual disability. A major component of the clinic's work is the assessment and management of people with Down syndrome and Alzheimer's disease. The CDDHV is involved in the education of general psychiatry trainees, advances trainees in psychiatry of old age and psychiatrists in the assessment and management of psychiatric disorder, including dementia, in older people with intellectual disabilities, however there is no recurrent funding the accredited training position.

A review of the Cognition Dementia and Memory Service (CDAMS) clinics in Victoria [19] concluded

CDAMS clinics are currently seeing small numbers of older people with an intellectual disability who may also have dementia. Although present numbers are small, they are projected to increase substantially over the next 20 years.

If the provision of appropriate assessment and support services to people with intellectual disability who also have age-related cognitive decline/dementia is accepted as a legitimate role of the CDAMS clinics, then resourcing, training and support of CDAMS clinicians will be required in order to develop the necessary confidence and expertise. Clinicians will also need to be aware of a range of additional services and be able to engage disability services and aged care services to work together for the benefit of the older person with an intellectual disability, and CDAMS will need to develop collaborative relations with appropriate disability services to ensure effective care planning.

Recommendation 6

That the provision of assessment, diagnosis and support services to people with intellectual disability who have age-related cognitive decline/dementia is accepted as a legitimate role of some, if not all, CDAMS clinics and that clinics be developed to reflect this.

A non funded working party has been convened to look at ways of implementing this recommendation. This initiative is being driven by individual clinicians in their own time and has no funding or programmatic support.

The Australian Institute of Health and Welfare Report into Disability and Ageing [20] recognizes the issues of service transition from state funded specialist disability services to federally funded generic aged care services versus ageing in place and acknowledges that this can be a grey area. Currently there is a policy vacuum. For example when a person with Down syndrome living in a community residential unit (CRU) develops Alzheimer's disease and requires higher levels of care, where does and should the funding for this come from? Do disability services provide for increased staffing, or should current staff be expected to provide the increased level of care at the expense of the needs of the other residents in the CRU? Or should the increased level of care be funded from the aged care budget in the form of a community care package? Without the increased level of support to enable ageing in place for older people with intellectual disabilities the solution will be to move people prematurely from their "homes" to aged care facilities. If people are moved into aged care facilities then links to the community and day programs need to be maintained. This is usually not the case.

- ***Policy rhetoric needs to be matched by funded programmatic responses***
- ***Development of curricula for health professionals and funding for training are required***

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