Questionnaire:
Proposed Strategies for Dementia Care and Support in Victoria 2005 and Beyond

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Please find enclosed a submission I made to the recent CDAMS review and a copy of the Edinburgh Principles (Wilkinson and Janicki 2002).

My responses to the framework are focused on people with intellectual disability. I am encouraged to see that people with Down syndrome and Alzheimer's disease are mentioned in this framework (p16). However people with intellectual disability in general are also at increased risk of dementia compared with the general population (Cooper 1997). This group also needs to be considered.

The state disability plan (State Government of Victoria Department of Human Services 2002) makes it clear that people with disabilities have the same rights and responsibilities as everyone else in the community. To sum up the Edinburgh Principles (Wilkinson and Janicki 2002) people with intellectual disabilities and dementia should receive the same access to and quality of services as anyone else with dementia. However the configuration of current services and funding arrangements between the state and federal governments make negotiating care pathways uncertain and complicated for the person with dementia, carers, family and service providers.

Demographics

Older people with intellectual disability are a relatively small but rapidly growing population. What information is available on the demographics of older people with intellectual disability in Victoria? How many people with DS age >40 years live in Victoria? Where do they live?

A working party is currently being convened to examine how CDAMS clinics can best respond to people with Down syndrome and Alzheimer's disease and other people with intellectual disability and dementia. The first question on the agenda regards demographics. Without basic demographic data rational service planning and responses cannot proceed.

Question A

Preventing and reducing risks of dementia – health and active living

What strategies can you suggest to ensure that the interests of special needs groups are met?

Currently there is not a coherent approach to the health care of people with intellectual disabilities. Planning for health care is not required in general service plans. People with intellectual disabilities receiving formal state care do not hold personal health records. Instead their health and medical information is dispersed through their general files. For older people this could mean health information archived in multiple files, in some instances 15 or more files.

The increased prevalence of dementia in people with intellectual disability as noted by Cooper (Cooper 1997) needs to be explained. My professional opinion based upon people I have seen at the Psychiatric Clinic for Older People at the Centre for Developmental Disability Health Victoria is that people in middle age are presenting with significant cerebrovascular disease. It is possible that the excess dementia seen in people with intellectual disabilities is due to vascular dementia which should be amenable to preventative health measures addressing vascular risk factors. People with a range of genetic syndromes are at risk of hypertension, diabetes and dyslipidaemias and hence cardiovascular and cerebrovascular disease (Wallace 2004). This can increase the risk of both vascular and Alzheimer's disease.

My recommendation would be that people with intellectual disability cared for under the auspices of Disability Services should have annual health checks including assessment for and management of vascular risk factors. Programs to address diet and exercise are also required.

About 50% of people with Down syndrome will develop Alzheimer's disease in the 6th decade (Holland 1998), although figures vary from study to study. There needs to be a systemic approach to conducting, documenting baseline and regular reviews of function for all people with Down syndrome registered with Disability Services. This will allow for early detection of functional decline and future planning. Whilst preventive or course altering treatments for Alzheimer's disease are not yet available it is expected that such treatments will be available in the not so distant future.

Accommodation and Care Planning for People with Intellectual Disability and Dementia.

Current policies and funding for services encourages people with dementia to remain in their own homes or with family for as long as is safe and or practicle. How is ageing in place to be facilitated for people with intellectual disabilities? How is this to be funded? Will funding be available from the aged care budget or from the disability budget? What agreements will be made between state and federal governments on this issue?

I am aware that some community residential units with a focus on older people with intellectual disability have been established. I am also aware of people with Down syndrome and Alzheimer's disease who have been living with elderly mothers who also have Alzheimer's disease. At least one of these men was placed in a community residential unit with a focus on older people. This is a positive development. However staff at these CRUs have told me that they have not received any specific training in aged care or in dementia care.

Services such as ACAS need to understand that people with Down syndrome may have Alzheimer's disease at age 45 and is just as entitled to services as someone who is 80 years old with a dementia. Assessment for dementia in people with intellectual disability needs to be informed so that other causes of functional decline are not overlooked.

Also services need to be able to make distinctions between older people with intellectual disabilities and age related problems such as dementia and a health survivor population. Some rural CDAMS services are under pressure to see older people with intellectual disabilities to diagnose "dementia" to facilitate age care placements. Clearly this is not the role of CDAMS. This should be the role of ACAS. However placement in a nursing home is not the best option for healthy older people with intellectual disability who need placement when their parents are now not able to care for them.

References

Cooper, S. A. (1997). "Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities." British Journal of Psychiatry **170**: 375-80.

> BACKGROUND: The literature regarding psychiatric illness among elderly people with learning disabilities is limited and conflicting because of methodological differences. There have been no recent studies comparing psychiatric epidemiology between younger and older adults with learning disabilities, using the same methodology and definitions. METHOD: Comprehensive psychiatric examination using a semi-structured rating scale was

undertaken on everyone with learning disabilities, aged 65 years or over (n = 134), living in a defined geographical area. Comparison was made with a randomly selected control group of adults with learning disabilities aged 20-65 years (n = 73) drawn from the same geographical area. RESULTS: Elderly people with learning disabilities have a greater prevalence of psychiatric morbidity than younger controls (68.7 v. 47.9%). Rates for depression and anxiety disorders are high, and dementia is common: there are equal rates for schizophrenia/delusional disorders, autism and behaviour disorders in the two groups. CONCLUSIONS: The higher psychiatric morbidity among elderly (compared with younger) people with learning disabilities has not previously received adequate recognition. This warrants further investigation by service planners and clinicians.

Holland, A. J. (1998). Down's syndrome. Dementia, Aging and Intellectual Disabilities: A Handbook. M. P. Janicki and A. J. Dalton. Philidephia, Bunner/Mazel**:** 183-193.

State Government of Victoria Department of Human Services (2002). State Disability Plan 2002-2012. Melbourne, Disability Services Division, Victorian Government Department of Human Services.

Wallace, R. (2004). "Risk factors for coronary artery disease among individuals with rare syndrome intellectual disabilities." Journal of Policy and Practice in Intellectual Disabilities **1**(1): 31-41.

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

A panel of experts attending a 3-day meeting held in Edinburgh, UK, in February 2001 was charged with producing a set of principles outlining the rights and needs of people with intellectual disability (ID) and dementia, and defining service practices which would enhance the supports available to them. The Edinburgh Principles, seven statements identifying a foundation for the design and support of services to people with ID affected by dementia, and their carers, were the outcome of this meeting. The accompanying guidelines and recommendations document provides an elaboration of the key points associated with the Principles and is structured toward a four-point approach: (1) adopting a workable philosophy of care; (2) adapting practices at the point of service delivery; (3) working out the coordination of diverse systems; and (4) promoting relevant research. It is expected that the Principles will be adopted by service organizations world-wide, and that the accompanying document will provide a useful and detailed baseline from which further discussions, research efforts and practice development can progress. (PsycINFO Database Record (c) 2002 APA, all rights reserved) (journal abstract).