

## **Understanding the dynamics of planning and providing accommodation services for people with Intellectual Disability**

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### **ABSTRACT**

Accommodation support for people with Intellectual Disability is a major component of public expenditure in the Australian welfare setting. Along with the ageing of this population over the past three decades there have been major shifts in the philosophy of care which have had impact upon funding policies and the allocation of resources. The signing of the UN Convention on the Rights of Persons with Disabilities has prompted a review of current programs and more comprehensive planning for improvements.

System dynamics modeling software was used to understand the implications for service provision of the ageing of this group. A community prevalence of approximately 0.8% was established, with a baseline of approximately 0.1% of the population requiring formal accommodation support and this was incorporated into the expected changes which will occur in the Australian population. Modeling of changes in level of intellectual impairment and levels of dependency in four age groups over the next forty years predicts a rise in the numbers of middle aged and older adults with Intellectual Disability needing accommodation support.

Changes in the levels of demand in each form of accommodation were estimated by 'what-if' experimentation with changes in eligibility criteria. There will be a substantial rise in the intensity and demand for state funded disability accommodation, as the clients themselves and their parents age, with little change in the need for aged care accommodation.

**KEYWORDS** Intellectual Disability, Health Policy, Cognitive Impairment, System Dynamics

## **INTRODUCTION**

Australia's signature to the UN Convention on the Rights of Persons with Disabilities [UN,2008] has highlighted its commitment to planning for health and habilitation services (Article 26). In this exercise we utilized a system dynamics approach to planning for accommodation service for people with Intellectual Disability. The International Classification of Functioning, Disability and Health (ICF) [WHO 2001] defines 'intellectual disability' as a lack or loss of cognitive ability ie the incapacity to think, to calculate, to remember, to communicate, to relate to other people. It is an overarching descriptor and it is estimated that approximately 3% of the world's population may have an intellectual disability [WHO 2007].

When used in health care and social welfare settings the term has a more specific meaning. A person has Intellectual Disability (also known as Learning Disability and Mental Retardation) if her/his cognitive difficulties arose in childhood, and they have resulted in the need for support from another person in those and other areas of functioning [Luckasson 1992]. Intellectual Disability is a lifelong disability, caused by damage or delay in development of brain function. It is sometimes associated with other neurologically determined disorders such as epilepsy, movement disorders and paralyses, and bladder and bowel dysfunction; any and all of which may also be severe enough to need another person for daily support.

It is estimated that approximately 0.8% of the Australian population has Intellectual Disability [ABS 2004, AIHW 2008] and that while more than half this group are still under the age of 20 years [Leonard 2002], the older group is growing as their longevity increases [AIHW 2006]. People with Mild Intellectual Disability now have a life expectancy approaching that of the general Australian population and even those with Severe-Profound Intellectual Disability can expect to live into their fifties. [Bittles 2002]

Social policy for care of people with Intellectual Disability has shifted in developed countries over the past fifty years from an institutional nursing model to provision of less restrictive community group home accommodation accompanied by living skills support, as well as increased support for people to continue living with their families. Over 70% of state government disability budgets in Australia is spent annually on accommodation support and over 90% of the recipients of disability accommodation support are people described as having Intellectual Disability. [AIHW 2006]

In spite of these significant funding allocations for supported accommodation for people with Intellectual Disability there has been little formal planning and the emerging gap between supply and demand is now visible as unacceptable waiting times for permanent places, permanent occupancy of overnight respite beds, a rising number of young and middle-aged adults living inappropriately in aged care nursing-based accommodation and delays in the provision of facility and human resources.

The main confounders for planning have been shifts in the language used to describe and identify Intellectual Disability, paucity of prevalence data, inconsistencies in the eligibility criteria for funded accommodation, multiple avenues for support by both state

government disability and commonwealth government health authorities, and the systemic lag between acknowledgment of an issue (such as longevity) and the implementation of solutions.

Because simple service-related spreadsheets could not accommodate these complexities usefully we chose to use system dynamics tools to articulate this situation and plan for improvements [NHS Confederation 2005].

## **AIMS**

The overall aim of this modeling project was to understand the whole of life care needs of people with Intellectual Disability and consider the accommodation support funding implications of the demand created by the ageing of this population. The objectives were

1. To build a computer model of the prevalence of people with Intellectual Disability;
2. To depict the changes over time which occur in people with Intellectual Disability in dependency and need for accommodation support; and
3. To run virtual policy experiments on these depictions to establish the demand for accommodation support over the next forty years.

## **METHODOLOGY**

The investigating team consisted of a Rehabilitation Physician with expertise in Intellectual Disability, who is also a Health Administrator; a Specialist Physician with expertise in health system dynamics; and an Engineer with expertise in system dynamics modeling. The process began with brainstorming the issues and causes, using concept maps and causal loop diagrams to develop a dynamic hypothesis. It continued with iterations of developing the computer model using *iThink* software, searching for the data that was needed to initialise and calibrate the model stocks and parameters, reworking the model as more data became available and testing policy scenarios by designing and running virtual experiments. The model parameter values are tabulated in the supporting file accompanying this conference paper.

## **BACKGROUND**

The setting is the state of New South Wales (NSW) in south eastern Australia, with a population approaching 7M in 2009. It is estimated that approximately 0.8% of the population meets the criteria for definition of the phrase Intellectual Disability (60,000) and it is known that there are 28,000 (0.4% population) people with Intellectual Disability [AIHW 2006] who are annually in receipt of disability services such as accommodation, respite, therapy, activities or special employment. In 2007 the cost of the accommodation services supporting them was in the order of \$A800M. [DADHC 2008]

In 2009 there were 7,000 funded disability supported accommodation places in NSW – 6,700 were occupied by people with Intellectual Disability - some 5,000 in group homes and other forms of support, and there are still 1,700 in large residential settings (in devolution). Approximately 2,000 people receive 24 hour Registered Nurse care in both these settings, and they range in age from 16-85 years. A proportion of the people living with RN support in the large residential settings are in receipt of that level of care because it came with the site when they entered the residence and it has not been through its transition to combination staffing yet.

In 2009 there were 24,000 Commonwealth Health funded Aged Care places in NSW. It is estimated that there are 500 people with Intellectual Disability living in nursing homes and 300 in aged care hostels, with 24 hour registered nurse (RN) cover [Bigby 2008]. The persons with Intellectual Disability living in this accommodation setting range in age from 35-85 years. Not all these people living in this form of care are actually in need of RN interventions.

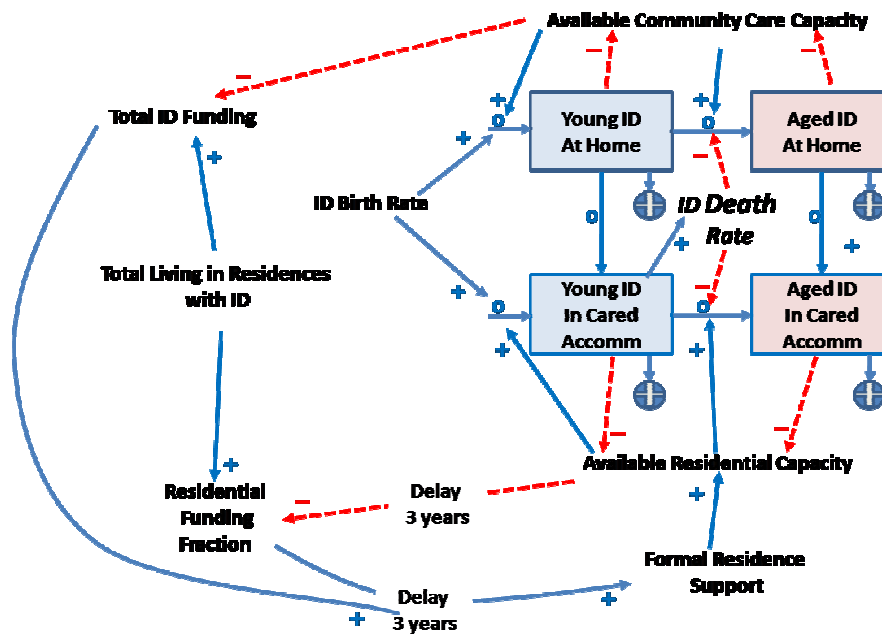
The current policy is to continue to provide more group home places and completely close the large residences staffed by Registered Nurses (RNs) and funded by Disability Services, over the next ten years. There will be a reduction in the number of people provided with disability accommodation support by RNs, with this form of care being reserved, in group homes, for those people who actually need RN interventions, and the bulk of formal support will be provided by trained personal care attendants.

This modeling exercise was undertaken to quantify the demand for different forms of accommodation support over the next forty years and consider ‘what –if’ scenarios in relation to the policy and funding responsibility changes that might occur.

## THE SYSTEM

A simplified diagram of the main stocks, flows and causal influences is depicted in Figure 1.

Figure 1. Factors influencing the balance of supply and demand for care of people with intellectual disability.



## THE MODEL

Using the *ithink*® software we began with development of the model of prevalence of Intellectual Disability. There is no register of people ‘diagnosed’ with Intellectual Disability in Australia. However a national Survey of Disability, Ageing and Carers (SDAC) has been conducted every five years since 1988 and iterations have asked for successively more definitive data. Analysis of data cubes on the website of the Australian Institute for Health and Welfare from the 2003 survey reveals that approximately 1% of the population have low intellectual functioning from early childhood; and approximately 0.8% have lifelong significant intellectual impairment that arose in childhood, that is associated with difficulties in communication, daily activities or mobility. Approximately half the group are children, and half are adults. [AIHW 2006a, 2006b ]

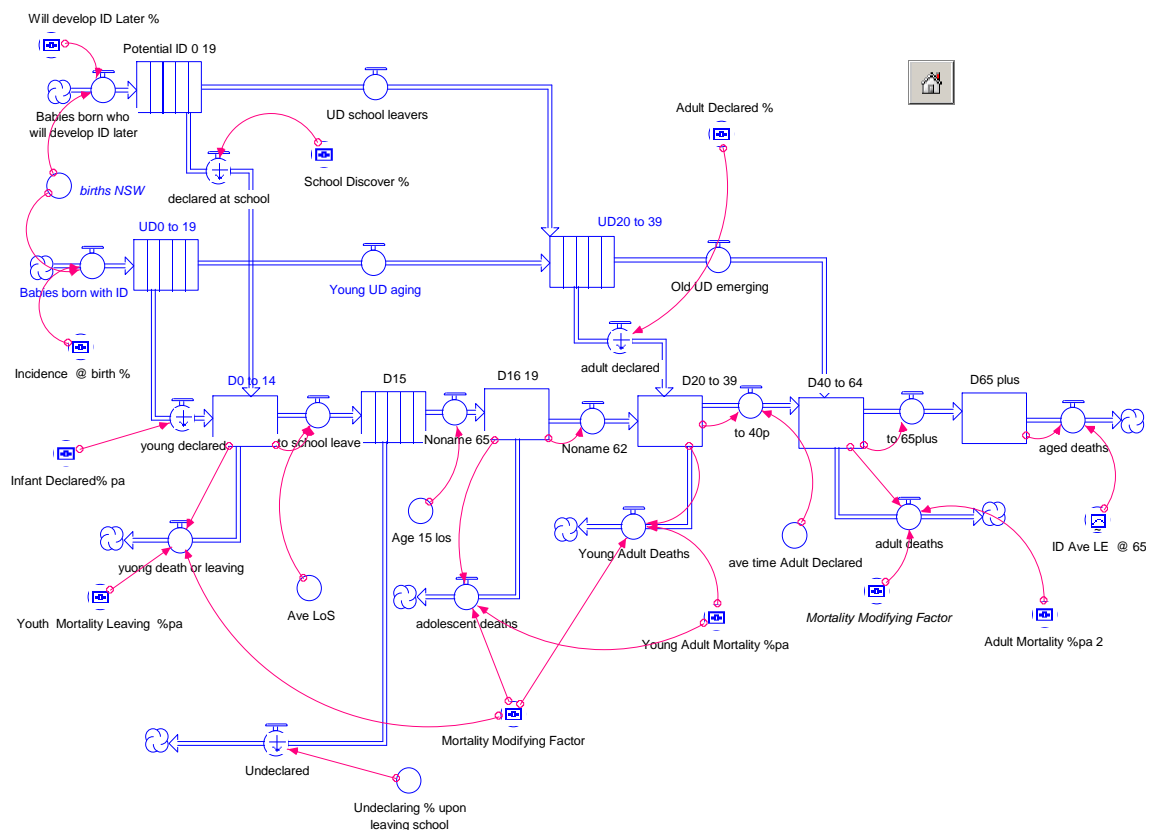
This estimate of 0.8% of the population, then, was used in this modeling exercise as the prevalence of people with Intellectual Disability and we assumed continuation of the components of this base rate over the forty years of the model.

Our ageing (flow) chain consisted of five stocks by age groups 0-15years, 16-18yrs, 20-39years, 40-64 years and 65+ years. These groupings were chosen for their policy implications:

- '18 years' is the cut-off time for medical diagnosis of the descriptors 'intellectual disability', 'developmental delay' and 'autism';
- transition from paediatric to adult healthcare services is completed by 19 years.
- '40 years' appears to be a clinically significant time for onset of early neurological ageing in people with Intellectual Disability; and is the time at which ageing parents are retiring and not able to financially or physically care for their dependent middle aged children; and
- '65 years' is the age for eligibility for the Age Pension in Australia.

People with Intellectual Disability are usually detected soon after birth and become known to the formal health and disability care systems. They make up the bulk of those "declared" (D0 to 19) by the age of 18 yrs as depicted in the stock flow diagram, Figure 2.

Figure 2 *ithink Model Prevalence Sector for declared Intellectual Disability*



A smaller number of people appear normal at birth and develop Intellectual Disability later in childhood ie the stock of “potential” ID 0-19. People with ‘Undeclared’ Intellectual Disability join the group of ‘Declared with Intellectual Disability’ at three stages in their lives:

- Mostly before the age of 18 years, having been diagnosed as babies, at school entry or at high school entry (D0 to 19);
- During early adulthood when application for disability pension may be sought (D20 to 39); and
- In later adulthood (D40 to 64) when the death or infirmity of parents or other family members may leave the person with disability without support and seeking formal care.

We set our 2003 starting population at 56,000:

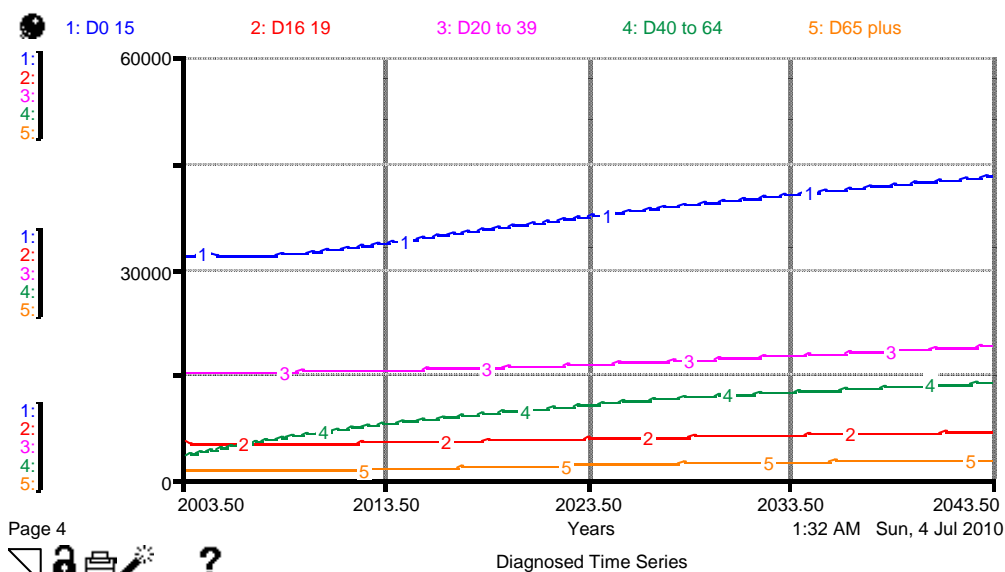
- 31,700 (56%) people aged 0-15 years,
- 5,000 (9%) people aged 16-19 years,
- 15,000 (27%) people aged 20-39 years,
- 3,200 (6%) people aged 40-64 years, and
- 1,100 (2%) aged 65+ years.

## RESULTS

### Prevalence

Figure 3 demonstrates that we are able to make predictions for the population of people with Intellectual Disability in the five age groups. During the next forty year period the number of declared people in the older age groups is likely to continue to grow for at least thirty years. We also note that there is an expectation of rise in prevalence in the youngest age group. .

Fig. 3 Declared ID Population by Age Groups from 2003 to 2043



### Level of Intellectual Disability

The computer modeling demonstrates in Figure 4 that the numbers of people in each of the Moderate, Severe and Profound levels of Intellectual Disability will not change much over the forty year period, but the numbers in the Mild Intellectual Disability group will rise by 40%.

Fig 4 Prevalence of levels of Intellectual Disability

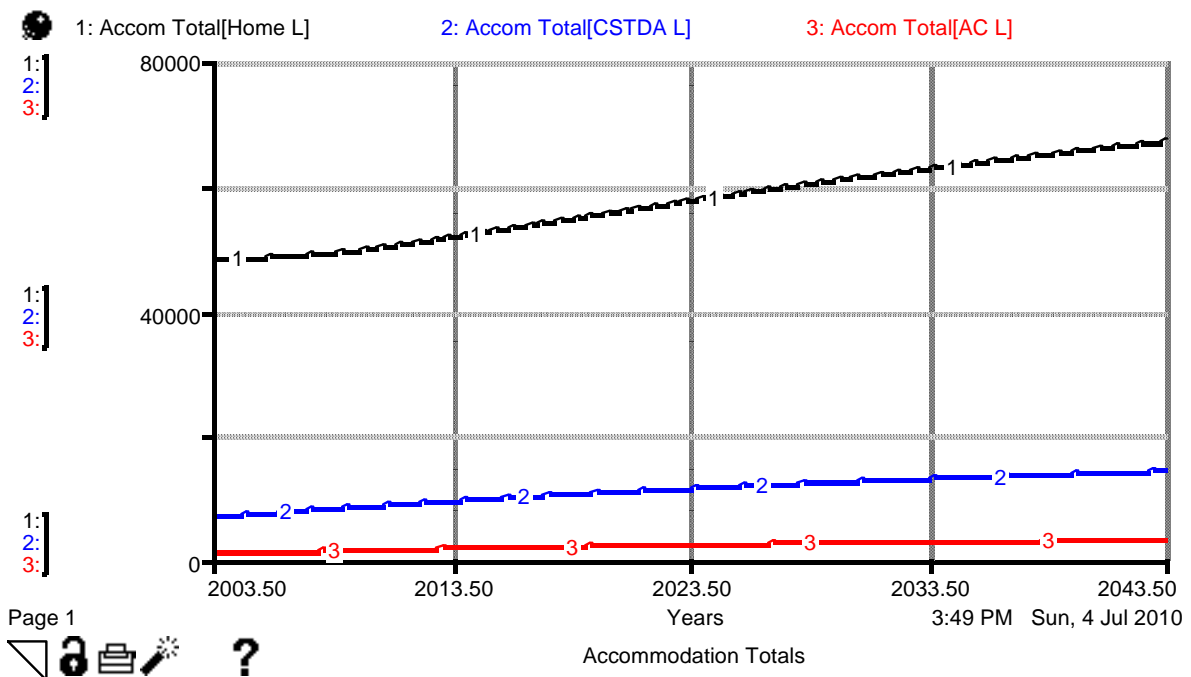




### Accommodation settings

Using the model we were able to estimate the future growth in demand for out of home care with confidence. Figure 5. The funding implications for whichever government body would be providing the service could be calculated and considered. The state funded system was providing approximately 7,000 places in 2003 [DADHC Annual Reports]. The commonwealth funded aged care provision was approximately 800 places in 2003. The demand will rise over ten years to 9,000 and 1,600 places respectively and will not plateau (at 12,000 and 2,500) until 2030.

Fig 5 Accommodation sites 2003 – 2043



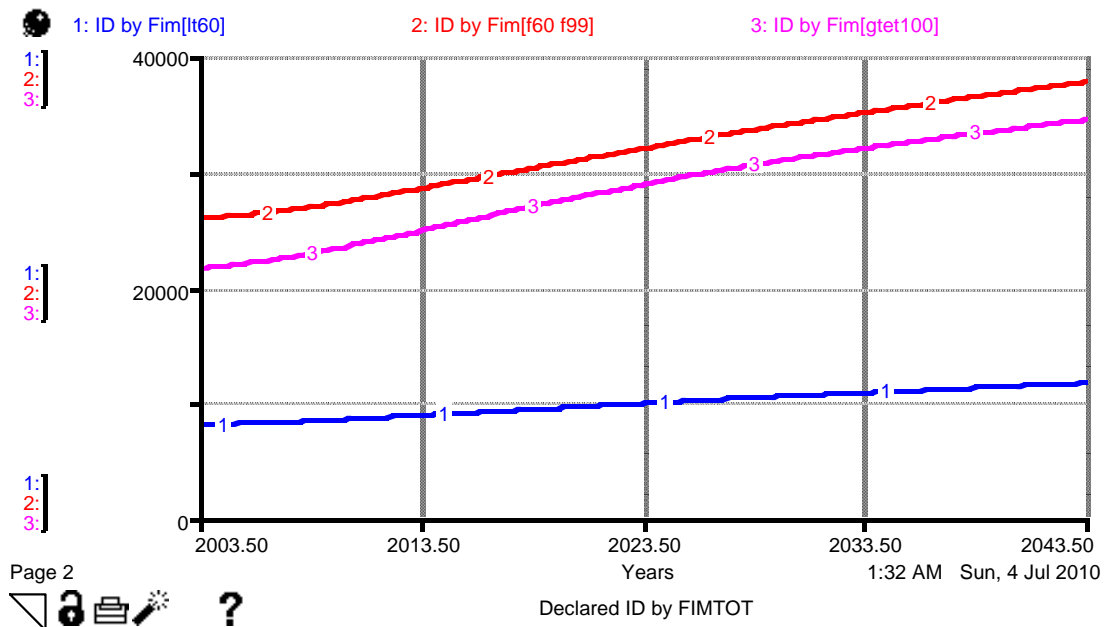
### Intensity of support needed

By extrapolation of data from a cross sectional study of 500 adults and an epidemiological study of 160, referred to the Developmental Disability Clinic at Concord Hospital, to the population groups, estimates of prevalence of need for assistance in daily living were made, based on the assessed Functional Independence Measure [UDSMR 2010]. Prevalence of need for intermittent, intensive and pervasive care based on FIM Total scores were superimposed on the prevalence of levels of Mild, Moderate, Severe and Profound in each age group.

The FIM records a score from '1' – fully dependent, to '7' – independent on thirteen physical domains, and five cognitive domains which are then added. A FIMTOT of 100-126 indicates a need for Intermittent (supervisory daily) care, 60-99 a need for Intensive (hands-on daily support) care, and 18-59 a need for Pervasive (24-hr) care.

The graph in Figure 6 demonstrates that the greatest rise in need will be in the Intermittent and Intensive need groups. The numbers of people needing pervasive (or nursing-home-type) care will not rise significantly. Costs of care in each group can now be used for multiplication by estimated numbers to predict overall costs for planning purposes.

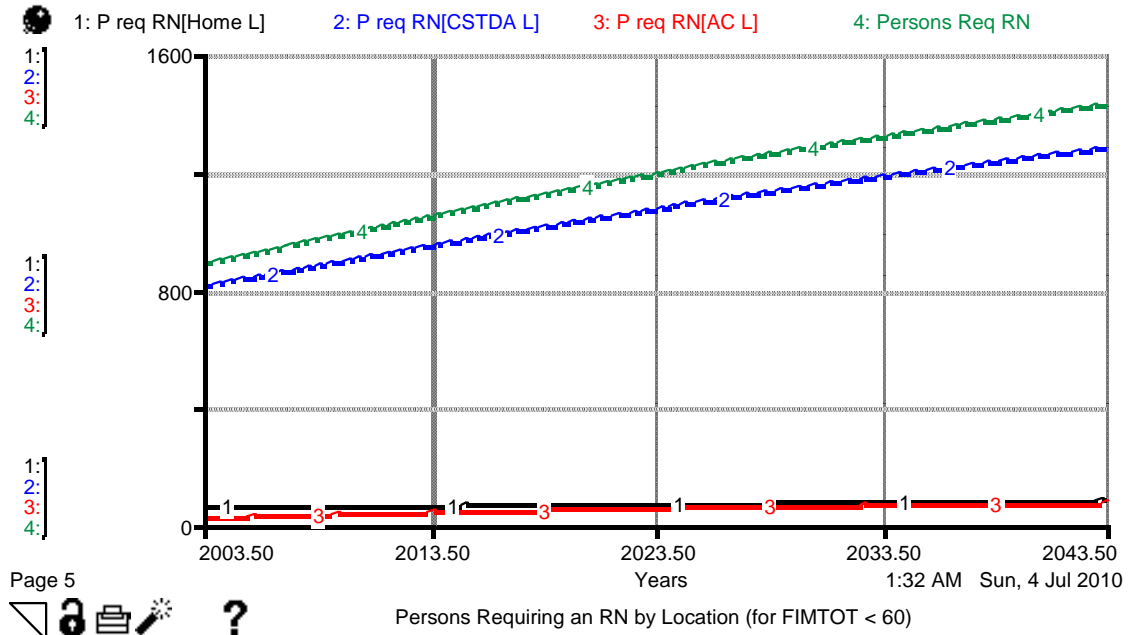
Fig. 6 Intensity of need for support



### Need for Registered Nurse support

Again using the figures from the Clinic database, extrapolations were made on the rates of people with a FIMTOT less than 60, who also needed Registered Nurses on a daily basis for maintenance of their health. The numbers of people requiring RN support will rise, for at least the next thirty years and if there is no change to policy, it will be the state disability system which will need to accommodate this rise. The actual numbers, however, are small – there will be approximately 1300 in need of 24 RN support – and this is less than the numbers currently in receipt of that form of support at this time. Fig 7

Fig 7 Registered Nurse Service Need from 2003 to 2043



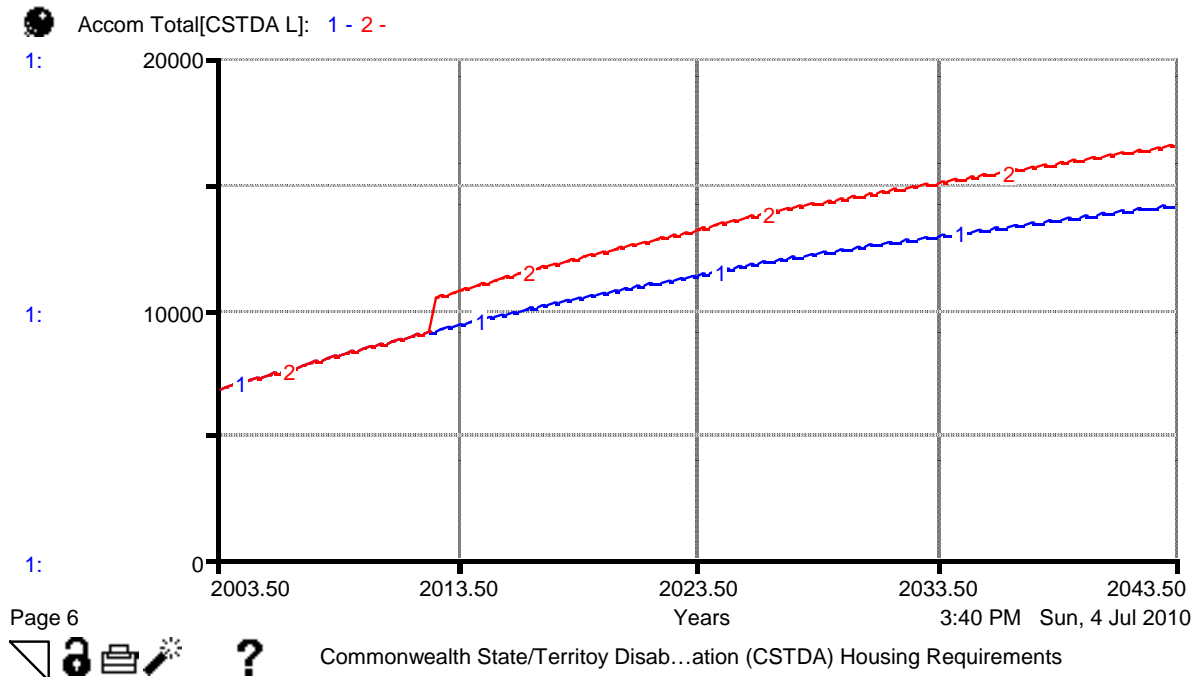
### What-if scenarios

Using the model we were able to answer an important policy question about out-of-home care. While the prevalence of people with Intellectual Disability will grow only slightly over the next forty years, there will be a rise in the numbers of middle aged adults with mild intellectual disability who need out of home accommodation support. Currently these people are accommodated as children and young adults, at home, in disability accommodation and in aged care accommodation. As the parents of those at home, age, and no longer have the physical or financial resources to care for their middle aged and older adult children, the demand for out of home care will rise.

Those currently in disability accommodation are beginning to become more dependent, as they age, and the cost of their care is rising. Although small in number there is a group who are entering aged care - RN supported accommodation – early, and staying for many years in unacceptable institutional settings. Our model predicts considerable implications for the state disability system.

There is currently a ten year lead time for the set up of a group home and the model predicts a need for a rise of 100% over the current provision by 2030. If an attempt is made, by direct policy, to shift entry of people who do not need RN care from aged care to disability care, the need for places in 2030 in disability care will rise to 120% increase over current provision. Figure 8.

Fig 8 Accommodation demand in Disability support if people with ID under 65 no longer admitted to Aged Care places from 2010



## DISCUSSION

The most important question for policy makers in this decade of the launch of the United Nations Convention on the Rights of Persons with Disabilities, is the prevalence of Intellectual Disability, since this form of disability is the one which creates the greatest need for support and costs the most in terms of human resources committed to that support.

Brainstorming the mindmap of various stakeholders' views of the prevalence of Intellectual Disability was illuminating for the investigation team:

- Advocacy organizations and groups of clinicians who saw people with intellectual disabilities and numerous co-morbidities were adamant that numbers were high and there was a large unmet need for services in the community;
- service providers similarly saw a group with increasing needs as they aged; and
- funders were confused, and confusing, - publishing larger numbers of service recipients in some policy documents and smaller numbers in others.

It was the exercise of integrating the various disparate datasets and paying attention to ageing over time that finally brought clarity to the issue of prevalence. Three per cent of the population has difficulty with learning ie an intellectual disability, and 0.8% of the population meets the criteria for definition of Intellectual Disability.

The numbers to be targeted for service planning lie somewhere between these rates depending on the services being planned. So education services will need to target those in the school age group with learning difficulties of all forms, employment and activity services will need to target the smaller group of those in the working age range with more complex learning difficulties and support services for older people with disabilities will need to target those in the geriatric age range – or those in the working age group who have aged early.

In terms of Health services, General Practice planning needs to address the numbers of those with low intellectual functioning who are unable to take responsibility for their health and wellbeing themselves ie possibly all people with difficulty learning, or 3% of the population; while Specialist Health service planning need only look at those adults who meet the full criteria for diagnosis of Intellectual Disability and have complex health support needs ie possibly one third those who are known to the system, or 0.15% population.

The prevalence of those with full time accommodation support needs is even smaller (0.1% population) but it appears that their numbers are likely to double over the next thirty years and planning for the rate of this growth is an imperative.

Another enlightening moment came, again because of the need to seek out past data, when it became obvious that the numbers of people with Intellectual Disability living in supported disability accommodation in NSW had been stable at approximately 7,000 since 1980. This was inconsistent with the concept that the life expectancy of people with Intellectual Disability was rising and their dependency was rising as they aged; and the knowledge that their parents also were ageing and were probably not able to continue supporting them. We ‘found’ them living in the Aged Care sector.

It was very important to enlist a system dynamics approach to understanding the funding implications. Our model has demonstrated that the demand for places is likely to 100% more than has been available for the past thirty years and that demand, because of longevity, is likely to grow. The lag time and cost will be considerable and much more discussion will be required if these targets are to be met.

There are other groups of people who have neurological decline over time such as those with Multiple Sclerosis, Motor Neurone Disease and Dementia. Their numbers are also small but, like the ‘hidden’ group of people with Intellectual Disability who have been living with their parents until middle age, their entry to the service system may be precipitous and the system may not be ready for the substantial increase in public expenditure that will be needed.

## **CONCLUSIONS**

Key elements of sound service planning such as consistency of purpose, confidence in data and coherence of policy have been deficient in the area of accommodation support for people with lifelong disabilities in Australia. We may now be facing a crucial point in the evolution of social policy on caring for this vulnerable group of people as their life expectancy rises and the duration of demand for care increases.

The weakness in our ability to plan for this group is our reliance on surveys and cross sectional studies for spot prevalence of both the diagnosis of Intellectual Disability and the sub-groupings of levels of cognitive impairment and levels of dependency on other people. We await strong epidemiological studies for confirmation of these estimates. However the strength of the system dynamics approach is its ability to safely model what is and what could be happening over time, given the assumptions generated from the cross sectional estimates.

System dynamics modeling in the setting of planning for health and welfare service provision for people with Intellectual Disability has been a valuable tool – it has enforced discipline in the description of the prevalence, as well as in the search for understanding of the criteria for eligibility for services; and it has enabled a clear view of the implications of the changes which will continue to occur in both the people of interest and in the policies which will drive services for them.

## REFERENCES

ABS - Australian Bureau of Statistics (2004): cat No 4430 Disability Ageing and Carers Table 11 Persons with a Disability, Disability status by main health condition NSW 2003 [http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/CA2568A90021A807CA256F490071DFF8/\\$File/dac%20-%20state%20tables%20for%20nsw.xls](http://www.ausstats.abs.gov.au/Ausstats/subscriber.nsf/0/CA2568A90021A807CA256F490071DFF8/$File/dac%20-%20state%20tables%20for%20nsw.xls)

AIHW - Australian Institute of Health and Welfare (2008): Disability in Australia: intellectual disability. Bulletin no. 67. Cat. no. AUS 110. Canberra: AIHW

AIHW (2006a): Disability Support Services 2004-2005: National data on service provided under the Commonwealth State/Territory Disability Agreement. AIHW cat. No. DIS 46 Disability series. Canberra. Australian Institute of Health and Welfare

AIHW (2006b): Disability and Disability Services based on an extract of Australia's Welfare 2005. Table A5 Children with a disability p69. Cat No DIS43 Canberra. Australian Institute of Health and Welfare.

Bigby, C., Webber, R., Bowers, B., McKenzie-Green 2008: A survey of people with Intellectual Disabilities living in residential aged care facilities in Victoria. 52 (5): 404-414.

Bittles, A.H., Petterson, B.A., Sullivan, S.G., Hussain, R., Glasson, E.J., Montgomery, P.D. 2002: The influence of Intellectual Disability on Life Expectancy. J Geront. Med Sciences. 57(7): M470-M472

Cooper, S.A. (1997): Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. Br J Psych 170: 375-380.

DADHC - Department of Ageing, Disability and Home Care (2008): Annual Report. NSW Government.

Durvasula, S., Beange, H., Baker, W. 2002: Mortality of people with Intellectual Disability in Northern Sydney. Journal of Intellectual Disability 27(4): 255-264

Einfeld, S.L., Tonge, B.J. 1996: Population Prevalence of Behavioural and Emotional Disturbance in Children and Adolescents with mental retardation. 2. Epidemiological findings. Journal of Intellectual Disability Research, Vol 40, part 2, 99-109

Leonard, H., Wen, X. 2002: The epidemiology of mental retardation: challenges and opportunities in the new millennium. Ment Retard and Dev Dis Res Reviews 8: 117-134  
Cooper

Luckasson, R., Reeve, A. (2001) Naming, defining and classifying in Mental Retardation. Ment Retard 39 (1): 47-52.

The NHS Confederation (2005): The Potential of System Dynamics - A new era of strategic planning? In *Leading Edge* Issue 10  
[http://www.symmetricds.co.uk/files/le\\_systemdynamics\\_nov2005.pdf](http://www.symmetricds.co.uk/files/le_systemdynamics_nov2005.pdf)

United Nations (2007): UN Convention on the Rights of Persons with Disabilities  
<http://www.un.org/disabilities/default.asp?id=199>

UDSMR 2010: Uniform data set for Medical Rehabilitation.  
[http://www.udsmr.org/WebModules/FIM/Fim\\_About.aspx](http://www.udsmr.org/WebModules/FIM/Fim_About.aspx)

WHO (2001): International Classification of functioning, disability and health. Geneva: World Health Organisation.

WHO (2007): Atlas. Global resources for persons with Intellectual Disabilities. World Health Organisation.

Wullink, M., van Schrojenstein Lantman-de-Valk, H.M., Dinant, G.J., Metsemakers, J.F.M. 2007: Prevalence of people with Intellectual Disability in the Netherlands *JIDR* 51 (7): 511-519.



## APPENDIX Sources for the Intellectual Disability Accommodation Model

Table A1 Sources for Population

Name	Initial Stock or Parameter Value	Data Source
<b>Population</b>		
Initial_NSW_pop_June2003	6682053	Australian Bureau of Statistics Census data
Pop_0_to_19 Initial_NSW_pop_June2003*0.265	1770744	
Pop_20_to_49 Initial_NSW_pop_June2003*0.425	2839872	
Pop_50_to_64 Initial_NSW_pop_June2003*0.17	1135949	
Pop_65_Plus Initial_NSW_pop_June2003*0.14	935487	
<b>Fertility Rates</b>		
Mortality%_pa Population mortality 0-64yrs	(1994, 1.85), (1998, 1.78), (2002, 1.74), (2006, 1.80), (2010, 1.90), (2014, 1.90), (2018, 1.90), (2022, 1.90), (2026, 1.90), (2030, 1.90), (2034, 1.90)	Australian Bureau of Statistics
Ave LE at 65yrs	90	
PRAC_ave_LOS Av years lived as permanent residents of Aged Care Accommodation	2.5	Commonwealth Health and Aged Care
Net_migration = GRAPH(time)	(1990, 20000), (1995, 20000), (2000, 20000), (2005, 20000), (2010, 37500), (2015, 37500), (2020, 37500), (2025, 37500), (2030, 37500), (2035, 37500), (2040, 37500)	Australian Bureau of Statistics

Table A2 Sources for Intellectual Disability Stocks and Flows

Name	Initial Stock or Parameter Value	Data Source
<b>Intellectual Disability</b>		
D0_to_15 Declared Intellectual Disability 0-15yrs	31700	National survey Disability, Ageing and Carers
D16_to_D19 Declared Intellectual Disability 16-19yrs	5000	
D20_to_39 Declared Intellectual Disability 20-39yrs	15000	Australian Institute of Health and Welfare data cubes
D40_to_64 Declared Intellectual Disability 40-64yrs	3200	<a href="http://www.aihw.gov.au/disability/datacubes/index.cfm">http://www.aihw.gov.au/disability/datacubes/index.cfm</a>
D65_plus Declared Intellectual Disability 65+yrs	1100	Einfeld, Cooper
Potential_ID_0_19 Potential for ID, not yet declared	2400	Database at St George Diagnosis and Assessment Service
UD0_to_19 Undiagnosed 0-19yrs	1500	National survey Disability, Ageing and Carers
UD20_to_39 Undiagnosed 20-39yrs	750	
Adult_Declared_%	50	National survey Disability, Ageing and Carers
Adult_Mortality_%pa_2	2.5	NSW Registry Births Deaths Marriages
AR%[Declared_AgeNeeds]	0	
ave_time_Adult_Declared	20	Durvasula
Ave_time_Young_Declared	18	
Disability_Accom = GRAPH(time)	(2004, 6000), (2008, 6000), (2012, 6075), (2016, 6150), (2020, 6150), (2024, 6150), (2028, 6150), (2032, 6150), (2036, 6150), (2040, 6150), (2044, 6150)	Australian Institute of Health and Welfare Adjusted to NSW Population
ID_%_of_DA % Residents of Disability Accommodation who have ID	80	Bigby
ID_Ave_LE at 65 Life expectancy people with ID, at age 65rs	(2004, 70.0), (2008, 70.0), (2012, 70.0), (2016, 70.0), (2020, 70.0), (2024, 70.0), (2028, 70.0), (2032, 70.0), (2036, 70.0), (2040, 70.0), (2044, 70.0)	Bittles
ID_Ave_LoS_Prac People with ID average years in Permanent Residential Aged Care	10	Bigby
Incidence at birth_%	4	NSW Perinatal Statistics Unit

Infant_Declared%_pa	50	Author estimate
<b>Name</b>	<b>Initial Stock or Parameter Value</b>	<b>Data Source</b>
<b>Intellectual Disability</b>		
Registered2004[A0_19] Recipient of CSTDA services 0-19yrs	5200	CSTDA recipients
Registered2004[A20_39] Recipient of CSTDA services 20-39yrs	11900	Commonwealth States and Territories
Registered2004[A40_to64] Recipient of CSTDA 40-64yrs	7800	Disability Agreement
Registered2004[A65plus] Recipient of CSTDA services 65+yrs	1300	ie in receipt of Disability Services
School_Discover_%	90	Author estimate
Will_develop_ID_Later_%	0.2	Author estimate
Young_Adult_Mortality_%pa Diagnosed 20-39yrs	3	Durvasula
Youth_Mortality_%pa Diagnosed 0-19yrs	5	Durvasula

Table A3 Sources for Characteristics

Name	Initial Stock or Parameter Value	Data Source
<b>Characteristics people with Intellectual Disability</b>		
Receipt of AC accom 2004[A0_19]	0	Bigby
Receipt of AC accom 2004[A20_39]	50	
Receipt of AC accom 2004[A40_to64]	550	
Receipt of AC accom 2004[A65plus]	200	
Receipt of CSTDA Accom 2004[A0_19]	800	AIHW CSTDA data cubes
Receipt of CSTDA Accom 2004[A20_39]	3700	
Receipt of CSTDA Accom 2004[A40_to64]	2000	
Receipt of CSTDA Accom 2004[A65plus]	500	
FIM_Aged_Care_Accom_a_2[A0_19,lt60] % ID in Aged Care 0-19yrs, with FIMTOT<60	100	CERA database
FIM_Aged_Care_Accom_a_2[A0_19,f60_f99] % ID in Aged Care 0-19yrs, with FIMTOT 60-99	0	Centre for Education and Research on Ageing
FIM_Aged_Care_Accom_a_2[A0_19,gtet100] % ID in Aged Care 0-19yrs, with FIMTOT 100-126	0	500 adults with Intellectual Disability
FIM_Aged_Care_Accom_a_2[A20_39,lt60] % ID in Aged Care 20-39yrs, with FIMTOT <60	20	FIM Functional Independence Measure
FIM_Aged_Care_Accom_a_2[A20_39,f60_f99] % ID in Aged Care 20-39yrs, with FIMTOT 60-99	70	
FIM_Aged_Care_Accom_a_2[A20_39,gtet100] % ID in Aged Care 20-39yrs, with FIMTOT 100-126	10	FIMTOT Total scores
FIM_Aged_Care_Accom_a_2[A40_to64,lt60] % ID in Aged Care 40-60yrs, with FIMTOT<60	25	18=lowest, very dependent
FIM_Aged_Care_Accom_a_2[A40_to64,f60_f99] % ID in Aged Care 40-60yrs, with FIMTOT 60-99	50	126=highest, independent
FIM_Aged_Care_Accom_a_2[A40_to64,gtet100] % ID in Aged Care 40-60yrs, with FIMTOT 100-126	25	
FIM_Aged_Care_Accom_a_2[A65plus,lt60] % ID in Aged Care 65+yrs, with FIMTOT<60	15	
FIM_Aged_Care_Accom_a_2[A65plus,f60_f99] % ID in Aged Care 65+yrs, with FIMTOT 60-99	50	
FIM_Aged_Care_Accom_a_2[A65plus,gtet100] % ID in Aged Care 65+yrs, with FIMTOT 100-126	35	
FIM_CSTDA_Accom_a[A0_19,lt60] % ID in Disability accomm 0-19yrs, with FIMTOT<60	90	
FIM_CSTDA_Accom_a[A0_19,f60_f99] % ID in Disability accomm 0-19yrs, with FIMTOT 60-99	10	
FIM_CSTDA_Accom_a[A0_19,gtet100] % ID in Disability accomm 0-19yrs, with FIMTOT 100-126	0	

Name	Initial Stock or Parameter Value	Data Source
<b>Characteristics people with Intellectual Disability</b>		
FIM_CSTDA_Accom_a[A20_39,lt60] % ID in Disability accomm 20-39yrs, with FIMTOT<60	30	
FIM_CSTDA_Accom_a[A20_39,f60_f99] % ID in Disability accomm 20-39yrs, with FIMTOT 60-99	60	
FIM_CSTDA_Accom_a[A20_39,gtet100] % ID in Disability accomm 20-39yrs, with FIMTOT 100-126	10	
FIM_CSTDA_Accom_a[A40_to64,lt60] % ID in Disability accomm 40-64yrs, with FIMTOT<60	10	
FIM_CSTDA_Accom_a[A40_to64,f60_f99] % ID in Disability accomm 40-64yrs, with FIMTOT 60-99	40	
FIM_CSTDA_Accom_a[A40_to64,gtet100] % ID in Disability accomm 40-64yrs, with FIMTOT 100-126	50	
FIM_CSTDA_Accom_a[A65plus,lt60] % ID in Disability accomm 65+yrs, with FIMTOT<60	0	CERA database
FIM_CSTDA_Accom_a[A65plus,f60_f99] % ID in Disability accomm 65+yrs, with FIMTOT 60-99	20	Centre for Education and Research on Ageing
FIM_CSTDA_Accom_a[A65plus,gtet100] % ID in Disability accomm 65+yrs, with FIMTOT 100-126	80	500 adults with Intellectual Disability
FIM_Home_Accom_a[A0_19,lt60] % ID at home 0-19yrs, with FIMTOT<60	10	
FIM_Home_Accom_a[A0_19,f60_f99] % ID at home 0-19yrs, with FIMTOT 60-99	40	FIM Functional Independence Measure
FIM_Home_Accom_a[A0_19,gtet100] % ID at home 0-19yrs, with FIMTOT 100-126	50	FIMTOT Total scores
FIM_Home_Accom_a[A20_39,lt60] % ID at home 20-39yrs, with FIMTOT<60	20	18=lowest, very dependent
FIM_Home_Accom_a[A20_39,f60_99] % ID at home 20-39yrs, with FIMTOT 60-99	70	126=highest, independent
FIM_Home_Accom_a[A20_39,gtet100] % ID at home 20-39yrs, with FIMTOT 100-126	10	
FIM_Home_Accom_a[A40_to64,lt60] % ID at home 40-64yrs, with FIMTOT <60	5	
FIM_Home_Accom_a[A40_to64,f60_f99] % ID at home 40-64yrs, with FIMTOT 60-99	15	
FIM_Home_Accom_a[A40_to64,gtet100] % ID at home 40-64yrs, with FIMTOT 100-126	80	
FIM_Home_Accom_a[A65plus,lt60] % ID at home 65+yrs, with FIMTOT <60	0	
FIM_Home_Accom_a[A65plus,f60_f99] % ID at home 65+yrs, with FIMTOT 60-99	45	
FIM_Home_Accom_a[A65plus,gtet100] % ID at home 65+yrs, with FIMTOT 100-126	55	

Name	Initial Stock or Parameter Value	Data Source
<b>Characteristics people with Intellectual Disability</b>		
Level_of_ID_by_age_%_a[A0_19,Mild] %ID 0-19yrs whose disability is Mild	75	Einfeld
Level_of_ID_by_age_%_a[A0_19,Moderate] %ID 0-19yrs whose disability is Moderate	10	
Level_of_ID_by_age_%_a[A0_19,Severe] %ID 0-19yrs whose disability is Severe	12	
Level_of_ID_by_age_%_a[A0_19,Profound] %ID 0-19yrs whose disability is Profound	3	
Level_of_ID_by_age_%_a[A20_39,Mild] %ID 20-39yrs whose disability is Mild	40	Cooper, Wullink, CERA database
Level_of_ID_by_age_%_a[A20_39,Moderate] %ID 20-39yrs whose disability is Moderate	25	
Level_of_ID_by_age_%_a[A20_39,Severe] %ID 20-39yrs whose disability is Severe	18	
Level_of_ID_by_age_%_a[A20_39,Profound] %ID 20-39yrs whose disability is Profound	17	
Level_of_ID_by_age_%_a[A40_to64,Mild] %ID 40-64yrs whose disability is Mild	45	
Level_of_ID_by_age_%_a[A40_to64,Moderate] %ID 40-64yrs whose disability Moderate	25	
Level_of_ID_by_age_%_a[A40_to64,Severe] %ID 40-64yrs whose disability is Severe	16	
Level_of_ID_by_age_%_a[A40_to64,Profound] %ID 40-64yrs whose disability is Profound	14	
Level_of_ID_by_age_%_a[A65plus,Mild] %ID 65+yrs whose disability is Mild	65	
Level_of_ID_by_age_%_a[A65plus,Moderate] %ID 65+yrs whose disability is Moderate	26	
Level_of_ID_by_age_%_a[A65plus,Severe] %ID 65+yrs whose disability is Severe	8	CERA database
Level_of_ID_by_age_%_a[A65plus,Profound] %ID 65+yrs whose disability is Profound	1	
Need_RN%_Lt60[Home_L] Persons requiring RN (FIMTOT<60) at home	1	
Need_RN%_Lt60[CSTDA_L] Persons requiring RN (FIMTOT<60) in Disability accommodation	40	CERA database
Need_RN%_Lt60[AC_L] Persons requiring RN (FIMTOT<60) in Aged care accommodation	10	