



NSW Health

Analysis of costs and
benefits of specialised
intellectual disability
health services and
enhanced clinical
leadership

Service framework to improve
health care of people with
intellectual disabilities

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Executive summary

Aim and objectives

The aim of this project is to conduct an economic appraisal of the range of options presented in the draft *Service framework to improve health care of people with intellectual disabilities* (2007) and in particular to analyse the costs and benefits of options related to:

- specialised health services for people with intellectual disability (tier 4); and
- clinical leadership, research, and education and training for health professionals working with people with intellectual disability (tier 5).

The appraisal of costs and benefits of each option will inform a funding submission to be developed by NSW Health.

The Service Framework

The *Service framework to improve health care of people with intellectual disabilities* aims to promote a broader understanding of the health needs of people with intellectual disability and their right to effective services and care, and improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disability.

The Framework is based on a tiered approach that focuses on developing better understanding and capacity within the health system to:¹

- facilitate inclusion of children, adolescents and adults with intellectual disability into universal health services;
- provide additional specialist support where required across the spectrum of health needs; and
- respond more effectively and appropriately to the health needs of people with intellectual disability through specialist education, training, advocacy and research initiatives.

This approach has five tiers:

- *Tier 1:* Strategic health policy and population health
- *Tier 2:* Primary health and community health care
- *Tier 3:* Acute health care services
- *Tier 4:* Specialised intellectual disability health services, which relates to specialised assessment, intervention and treatment for people with intellectual disability and complex health needs and development of the health system's capacity to meet the needs of people with intellectual disability generally
- *Tier 5:* Statewide clinical leadership, research, education and training.

Options

The scope of the options considered are:

¹ NSW Health and DADHC (2007); *Draft Service Framework to improve health care for people with intellectual disability*.

Tier 4

- Establishment of a Clinical Nurse network across Area Health Services. There are two sub options considered - a network of clinical nurse consultants (CNCs), and a network of CNCs and clinical nurse specialists (CNSs).
- Establishment of small, specialised, multidisciplinary health teams across Area Health Services to provide specialised health services to people with intellectual disability, building on existing specialised services.
- Establishment of larger, specialised, multidisciplinary health teams across Area Health Services to provide comprehensive, specialised health services to children, adolescents and adults with intellectual disability, building on existing specialised services.

Tier 5

- Establishment of a clinical network to provide support and clinical leadership to health professionals working with people with intellectual disability, coordinate the development of intellectual disability health services, and to provide input into research, education and training.
- Establishment of three professorial chairs of intellectual disability medicine, intellectual disability nursing, and intellectual disability and allied health, linked to clinical services and faculties of medicine, nursing and allied health at appropriate universities.

Benefits

Specialised intellectual disability health services and clinical leadership, research, training and education will contribute to improving the health status and health outcomes for people with intellectual disability, as well as the quality of life of people with intellectual disability and their families and carers.

Specialised intellectual disability health services also have the potential to lead to real savings in health service and disability support costs through more intensive, earlier intervention, earlier diagnosis and detection of conditions, more effective management and treatment, and avoiding more costly health and disability interventions as health conditions progress. Case studies outlined in this report illustrate that the costs of specialised intellectual disability health interventions are relatively insignificant in most cases compared with the costs of health care in the absence of specialised services.

Investment in clinical leadership, research and education in intellectual disability health through a Greater Metropolitan Clinical Taskforce (GMCT) network and University Chairs, will contribute to improving the education and training of health professionals and increase their knowledge and capacity to work with people with intellectual disability, and will likely increase the number of health professionals with sufficient training to provide specialised intellectual disability health services in NSW. Further, research in intellectual disability health will be better coordinated and will contribute to a broader evidence base underpinning service delivery. Ultimately, these will improve the effectiveness of evidence-based service delivery and clinical practice.

Costs

The estimated recurrent costs of each of the tier 4 options are as follows:

Table 1 - Estimated recurrent costs of implementing tier 4 options

\$m	Option 1a - CNC network	Option 1b - CNC/CNS network	Option 2 - Small ID health teams	Option 3 - Full ID health teams
Estimated cost per annum ¹	1.364	4.575	19.013	52.561
Estimated Medicare revenue per annum ²	0	0	2.688	5.295
Estimated net cost per annum	1.364	4.575	16.325	47.267
Current funding (2008-09) ³	na	na	1.837	10.121
Estimated funding required per annum	1.364	4.575	14.488	37.146

Source: KPMG

Amounts expressed in 2009-10 dollars. Future years costs will increase by the level of cost escalation.

¹This represents the total recurrent cost of each option to the NSW Government. Costs include all staff costs and estimated non-staff operating costs per position, and include: salary costs, superannuation (9 per cent), workers compensation (2 per cent), and an allocation for general operating expenses per position (37 per cent) - as advised by NSW Health, and representing the NSW Health standardised costing method. Costing assumptions are outlined in Appendix B.

²This represents a cost to the Australian Government, and revenue for AHSs (hence offsets the total cost to the NSW Government). Assumptions relating to the calculation of Medicare revenue are outlined in Appendix B

³Note that these figures were collated through a survey of AHSs undertaken by NSW Health in 2009, and represent the best estimate of the level of funding allocated to specialised intellectual disability health services currently. For option 2, only those existing resources used to provide services to adults will offset the cost; for option 3, all existing resources will offset the cost. The accuracy of these figures have not been able to be verified by KPMG.

The estimated recurrent costs of each of the tier 5 components are as follows:

Table 2 - Estimated recurrent costs of implementing tier 5

\$m	GMCT network	University Chairs (x3)
Estimated cost per annum	0.287	1.260

Source: KPMG

Amounts expressed in 2009-10 dollars. Future years' costs will increase by the level of cost escalation.

Key findings

There is insufficient quantitative data and evidence to conduct a robust economic appraisal of the range of Framework options. At present there is no minimum State-wide data set on costs, service activity and the performance of existing services available to people with intellectual disability or evaluations of individual services.

However, based on available evidence and consultation, small multi-disciplinary intellectual disability health teams are likely to provide the highest net benefit in terms of cost effectively delivering improved health outcomes for people with intellectual disability.

The recurrent cost of implementing small intellectual disability health teams is estimated to be \$14.488 million per annum, net of Medicare revenue and existing resources allocated to specialised services for adults with intellectual disability.

The anticipated benefits of small multi-disciplinary teams include better coordination of health services for people with intellectual disability, more intensive, earlier intervention, earlier diagnosis and detection of conditions, and more effective management and treatment. These benefits are likely to result in avoided costs associated with early intervention.

There are workforce issues which will constrain the implementation of intellectual disability health teams in the short term, and additional costs are likely to be incurred as a result of any workforce development activities, including provision of training and education and financial and non-financial incentives. These costs have not been quantified.²

There is a need for additional, Statewide clinical leadership, and for improved coordination of education and training and research activities in the area of intellectual disability health. The appraisal suggests this can be best achieved through a GMCT-like network for intellectual disability health and University Chairs in Intellectual Disability Medicine, Nursing and Allied Health.

² However, the costs of ongoing training and professional development for staff employed in specialised intellectual disability health services have been included in the recurrent cost estimates for operating these services.

1 Project aims and scope

Project aims and scope

The aim of this project is to conduct an economic appraisal of the range of options presented in the draft *Service framework to improve health care of people with intellectual disabilities* (2007) and in particular to analyse the costs and benefits of options related to:

- specialised health services for people with intellectual disability (tier 4); and
- clinical leadership, research, and education and training for health professionals working with people with intellectual disability (tier 5).

The appraisal of costs and benefits of each option will inform a funding submission to be developed by NSW Health.

The scope of options to be considered are:

Tier 4

- Establishment of a Clinical Nurse network across Area Health Services.
- Establishment of small, specialised, multidisciplinary health teams across Area Health Services to provide specialised health services to people with intellectual disability, building on existing specialised services.
- Establishment of larger, specialised, multidisciplinary health teams across Area Health Services to provide comprehensive, specialised health services to children, adolescents and adults with intellectual disability, building on existing specialised services.

Tier 5

- Establishment of a clinical network to provide support and clinical leadership to health professionals working with people with intellectual disability, coordinate the development of intellectual disability health services, and to provide input into research, education and training
- Establishment of three professorial chairs of intellectual disability medicine, intellectual disability nursing, and intellectual disability and allied health, linked to clinical services and faculties of medicine, nursing and allied health at appropriate universities.

Economic appraisal methodology

An economic appraisal is a systematic method to analyse costs and benefits of a range of options. Economic appraisal techniques are used to compare whether the outcomes achieved as a result of the investment in a particular option justify the resources used.

Economic appraisal techniques rely on robust data, evidence and research to support and justify the analysis – and in particular the analysis of the cost effectiveness of alternative options. In the area of intellectual disability health services, rigorous data, research and evidence relating to the effectiveness of specific initiatives and interventions is very limited. While it has been possible to estimate the cost of alternative options proposed in this report, and identify the benefits of

options from a qualitative perspective it has not been possible to quantify the benefits of alternative options proposed. For this reason, a full economic appraisal has not been undertaken.

As an alternative, a 'case study' approach has been undertaken to illustrate the benefits of alternative options. The case studies relate to examples of clients who have or could have benefited from specific interventions, and illustrate the benefits or potential benefits of the intervention for that individual. Where possible, the benefits and costs of the intervention – as it relates to the individual – have been quantified. This has been discussed and agreed to by NSW Health and the Framework Advisory Group.

Outline of this report

This report is structured as follows:

Section two provides an overview of the health and health needs of people with intellectual disability, and outlines the components of the draft *Service framework to improve health care of people with intellectual disabilities*.

Section three describes the aims and purpose of specialised intellectual disability health services (tier 4 of the Framework), and a description of the options proposed.

Section four provides an analysis of the costs and benefits of the options for specialised intellectual disability health services.

Section five describes the aims and purpose of clinical leadership, research and education and training for health professionals working with people with intellectual disability (tier 5 of the Framework), the options proposed, and an analysis of the costs and benefits of these options.

Section six provides a summary of the options, costs, benefits, and implementation of specialised intellectual disability health services (tier 4) and clinical leadership, research and education and training (tier 5) components of the Framework.

In addition, appendices outline the underlying data, assumptions, and calculations for the costings of the tier 4 and 5 options proposed, current service provision data, and detailed case studies illustrating the benefits of specialised intellectual disability health teams.

2 Context and background

Introduction

This section provides an overview of the context for this project, including an overview of the services provided to people with intellectual disability, a summary of the health and health needs of people with intellectual disability, and an overview of the draft *Service framework to improve health care of people with intellectual disabilities*.

Services provided to people with intellectual disability

All people, including people with intellectual disability, can access a range of services funded or provided by Government, including education, health, transport, and public amenities. In the main, people with intellectual disability will access services in the same way as people without intellectual disability, though they may use services differently or use some services more or less often.

In terms of health services, people with intellectual disability access both 'universal' health services as well as some specialised services:

- people with intellectual disability access *universal health services* (such as general practitioner (GP) services, other primary health services, and acute hospital and specialist services). Some may access these services at a similar level or in the same way as people without an intellectual disability. For other people with intellectual disability with specific health needs, they may access some 'universal' services more or less frequently or at greater or lesser level of intensity than for people without an intellectual disability (such as some specialist medical services).
- some people with intellectual disability may also access *specialised health services* designed primarily for people with an intellectual disability, such as diagnostic and assessment services and the Developmental Disability Health Unit located in Ryde at the Royal Rehabilitation Centre Sydney.

It is important to distinguish between those services that support people with intellectual disability in their activities of daily living and in improving or maintaining their level of functional capacity (such as mobility, communication) to participate in their communities and those services that meet the health needs of people with intellectual disability. The former (disability services) are provided by the Department of Human Services (encompassing the former Department of Ageing, Disability and Home Care [DADHC]), while the latter (health services) are provided by NSW Health (Area Health Services [AHSs]). NSW Health and the Australian Government through the Medicare Benefits Scheme and Pharmaceutical Benefits Scheme may also have a role in improving, maintaining or improving function where this is related to physical or mental health.

The key difference is that disability services focus on daily living, support with activities of daily living, and maintaining, improving, or slowing any potential decline in functional capacity, whereas health services focus on the health and health needs of people with intellectual disability through treatment and management of health conditions which may or may not be associated with intellectual disability.

It is important to note that this report relates to health services for people with intellectual disability, rather than supports and services provided to assist people with intellectual disability with activities of daily living and maintaining or improving functional capacity.

Health and health needs of people with intellectual disability

People with intellectual disability have particular health needs and often face additional challenges in accessing health care compared with the general population. Current research shows that people with intellectual disability tend to have a higher level of morbidity than the general population, with health problems often being multiple, chronic and complex. Further, they have a higher prevalence of certain medical conditions, as well as lifestyle-related health risks such as obesity and poor physical fitness, and can experience greater barriers in accessing health care than those who do not have an intellectual disability.³

Prevalence studies have identified medical conditions and risk factors that occur more frequently in people with intellectual disability, including:

- oral health problems (including periodontal disease and severe malocclusion);
- nutrition problems (both underweight and overweight problems);
- vision and hearing impairment;
- cancer;
- accidents and injuries; and
- mental health problems (depression, dementia and schizophrenia occur more commonly than in the general population).⁴

Further, access to health care is one of the most significant challenges facing people with intellectual disabilities, and as a result a number of health conditions are more likely to be under-diagnosed and under-treated in people with intellectual disability. For example, a 1995 study of people with intellectual disability living in Northern Sydney indicated that the sample had on average 5.4 medical disorders per person, *half* of which had not been detected previously, and only half of diagnosed conditions had been appropriately treated despite reasonably good access to a range of health services.⁵

Reasons for this lower diagnosis and treatment include:⁶

- people with intellectual disability may have difficulty recognising and communicating symptoms of ill health (such as pain, discomfort, reduced physical or sensory ability) as a result of cognitive and communication impairments;
- fears of unknown places and situations, leading to non co-operative or challenging behaviour and difficulties in performing physical examinations;
- time taken to complete assessments because of the combination of communication difficulties, accurate history taking and physical examination;

³ Centre for Developmental Disability Studies. (2006) *Health Care in People with Intellectual Disability*. New South Wales.

⁴ Ibid.

⁵ Beange, H (1995): *Medical Disorders of Adults with Mental Retardation*, in American Journal of Mental Retardation, vol 99, no 6

⁶ Ibid.

- negative attitudes and perceptions about the quality of life of people with intellectual disability;
- the potential for diagnostic overshadowing whereby clinicians may ascribe physical or behavioural symptoms to the disability rather than looking for the underlying physical or mental health disorders;
- reactive delivery of health care, which relies on the individual seeking help, rather than the individual being routinely offered help;
- lack of knowledge/training about intellectual disability and associated health issues.

Further, a 2006 study examining the outcomes of health screening for people with intellectual disability - based on a sample of 50 people - found that health needs were detected at *twice* the rate in the study population undergoing health screening compared with the control population, that the level of new health needs that were met after one year was greater in the study population (3.56 needs/conditions met on average per son, versus 2.26 for the control population).⁷

Young people with intellectual disabilities (12 - 25 year age group) are at significant risk of mental health, medical, social, financial and forensic comorbidities as they fall in the gap between paediatric and adult services, education and day programs, and as they transition from their home to supported accommodation. The Garling Report highlights the needs of children and adolescents with mental health problems.

Currently there are a few coordinated specialist paediatric clinics for adolescents with intellectual disability in NSW and limited specialist adult health services. The efficacy of intervention at transition for this vulnerable group is well supported by evidence.⁸

Service framework to improve health care of people with intellectual disabilities

The draft *Service framework to improve health care of people with intellectual disabilities* (the Framework) has been developed by NSW Health in collaboration the former Department of Ageing, Disability and Home Care (now part of DHS).

The Framework recognises the significant progress in the provision of care and support for people with an intellectual disability in NSW, and in particular the move from institutionalising many people with intellectual disability to a focus on community inclusion and participation. With this move came an increased focus on the health and wellbeing of people with an intellectual disability. However, as part of this move, there was a reduction in the numbers of specialist medical staff - including doctors, psychiatrists, and mental retardation nurses - and a move towards people with intellectual disability accessing universal health services.

⁷ Cooper, A et al (2006): *Improving the health of people with intellectual disabilities: outcomes of a health screening programme after 1 year*, Journal of Intellectual Disability Research, vol 50

⁸ Calma (2008): *Preventing Crime and Promoting Rights for Indigenous Young People with Cognitive Disabilities and Mental Health Issues* Australian Human Rights Commission; Hayes S (2006) *People with intellectual disabilities in the criminal justice system - when is disability a crime?* Intellectual Disabilities in the Justice System, Sisters Inside Conference Brisbane; Barron DA et al (2007) *Transition for Children with Intellectual Disability*, St George's University of London, Learning about Intellectual Disabilities and Health; Murphy et al (1999) Identification of early self-injurious behaviour in young children with intellectual disability, Journal of Intellectual Disability Research, Vol 43, 3, June 1999, pp 149-163

It has become evident that the universal health service system does not always meet the health needs of people with intellectual disability - particularly those with complex needs.⁹ The Framework is a response to this shortfall, and aims to promote a broader understanding of the health needs of people with intellectual disabilities and their right to effective services and care, and improve the quality, range, consistency, accessibility and integration of services necessary to meet the health needs of people with intellectual disabilities.

A key component of the Framework is to ensure that people with intellectual disability are assisted by health professionals who understand and know how to respond to their specific needs.

The Framework is based on a tiered approach that focuses on developing better understanding and capacity within the health system to:¹⁰

- facilitate inclusion of children, adolescents and adults with intellectual disability into universal health services;
- provide additional specialist support where required across the spectrum of health needs; and
- respond more effectively and appropriately to the health needs of people with intellectual disability through specialist education, training, advocacy and research initiatives.

This approach has five tiers:

- *Tier 1:* Strategic health policy and population health, which relates to the promotion of the general health and wellbeing of people with intellectual disability and their carers.
- *Tier 2:* Primary health and community health care, which relates to primary intervention and early detection, and includes building the capacity and skills of the health system and health professionals to provide primary care to people with intellectual disability and detect health issues early, as well as building capacity of the health system to provide integrated health care and support,
- *Tier 3:* Acute health care services, which relates to the capacity of the secondary health care system to care for and manage the additional health care needs of people with intellectual disability who need to access hospital-based in- and outpatient services.
- *Tier 4:* Specialised intellectual disability health services, which relates to specialised advice, assessment, intervention and treatment for people with intellectual disability and complex health needs.
- *Tier 5:* Statewide clinical leadership, education, training and research.

This report focuses on tiers four and five of the framework, and these are described further below.

⁹ NSW Health and DADHC (2007); *Draft Service Framework to improve health care for people with intellectual disability*.
¹⁰ *ibid.*

Tier 4 - Specialised intellectual disability health services¹¹

People with intellectual disability will often require investigation and treatment across a range of health services. Access to services, co-ordination of services and support for individuals and their families are important elements in ensuring optimal health outcomes are realised for people with intellectual disability, particularly those with complex health needs.

Tier four services relate to specialised services provided for people with intellectual disability (and young children with developmental delay), and aim to:

- Provide multidisciplinary specialised health care assessment and clinical services to people with intellectual disability and complex health care needs across their life stages.
- Ensure continuous, comprehensive and co-ordinated health care by facilitating collaboration and co-operation within the hospital and community health care system as well as between the health and disability support systems.
- Increase the capacity of GPs and other medical and disability practitioners to meet the health needs of people with intellectual disabilities and their carers through the provision of education, training, specialist clinical support and consultancy.

Principles underpinning tier four services are:

- *Multidisciplinary* - approach to providing specialised care and support is based on multidisciplinary approach, utilising range of medical, nursing and allied health expertise working collaboratively
- *Lifelong* - specialised services should be available to people with intellectual disability/developmental disability of any age, and allow continuity of service across a person's life
- *Equitable* - opportunities to access services should be the same regardless of where a person lives, their age, or nature of disability (though recognising that target group is people with moderate or severe intellectual disabilities or developmental delay and/or people with mild intellectual disabilities or developmental delay and health care needs)

Tier 5: Statewide clinical leadership, education, training and research¹²

A tier 5 service has an oversight and leadership role for health services and health professionals working with people with intellectual disability, coordinating the development of services (and underlying systems), influencing and having input into the training and education of health professionals working with people with intellectual disability, shaping the research agenda and activities relating to intellectual disability health services.

This coordination and leadership function is necessary to ensure that both universal and specialised services are available and responsive to the needs of people with intellectual disability, that sufficient capacity exists in the health system to respond to the health needs of people with intellectual disability, and to promote evidence-based practice to ensure health outcomes for people with an intellectual disability improve.

¹¹ NSW Health and DADHC (2007); *Draft Service Framework to improve health care for people with intellectual disability*.

¹² Ibid.

3 Specialised intellectual disability health services – options

Introduction

This section provides a description of the options or proposed 'stages' of development of specialised intellectual disability health services in NSW in the short and longer term, along with a summary of current specialised service provision.

Current service provision

Some tier 4 services already exist in NSW, though these are primarily located in metropolitan areas and mainly focus on diagnosis and assessment of intellectual disability/developmental delay in children, rather than clinical services and coordination of services across the lifespan. There are few specialised intellectual disability health services for adults.

Specialised services provided currently include:

- Diagnostic and Assessment Services - multidisciplinary teams which provide diagnostic assessment services for children suspected of having global developmental delay or disability. Services may include identification of the cause or aetiology, determination of the extent of the disability, counselling, undertaking related assessments and developing a management plan. Two Diagnostic and Assessment Services provide services to adults as well as children.
- The Developmental Disability Health Unit (DDHU) - a service which provides specialised health assessments, care planning and referrals for adolescents and adults with intellectual disability. The DDHU is staffed by disability physicians, medical and psychology staff, and specialist medical staff from the Royal Rehabilitation Centre at Ryde. Clinics include general medical, Down Syndrome, Cornelia de Lange and Fragile X; rehabilitation; and ageing and dementia.
- other services and clinics for specific groups or conditions.

It is difficult to estimate the level of service provision or numbers of clients accessing existing specialised intellectual disability health services. This is because there is no common data definitions or data collection system relating to the types or levels of service provided by existing specialised services, numbers of clients or client characteristics, with each service generally keeping their own data - electronically or in paper-form.

However, there are some preliminary estimates of the level of resourcing allocated to specialised services provided by a survey of existing services undertaken by NSW Health in July 2009. The survey indicated that:¹³

¹³ NSW Health survey of existing specialised intellectual disability health services in July 2009. Collated survey data provided to KPMG by NSW Health in August 2009.

- there are 24 separate services, including 14 services for children with intellectual disability or developmental delay, seven services for adults with intellectual disability, and three services for both children and adults
- most services are relatively small (less than \$500,000 in expenditure per annum)
- all services are located in metropolitan Sydney, with the exception of two services located Greater Southern AHS, and some diagnostic and assessment services
- total staffing numbers (FTEs) amounted to approximately 101 FTEs in 2008-09. This is likely to be an underestimate of the number of staff given some clinicians who provide services (for example, through regular clinics) may be employed by other departments, and some services did not provide FTE data as part of the survey.

Estimated NSW Health expenditure on specialised services, based on survey responses, was approximately \$12.0 million in 2008-09, of which approximately \$10.1 million related to services specifically for children. Estimated expenditure is outlined in the tables below:

Table 3 - Specialised intellectual disability health services - estimated expenditure by service target group, 2008-09

Target group	No. of services	Expenditure (\$m)	Expenditure (\$m) ¹
Children	16	8.765	10.121
Adults	7	0.934	1.837
Both	3	2.259	...
Total	26	11.958	11.958

Source: NSW Health survey of existing specialised intellectual disability health services, provided to KPMG by NSW Health in August 2009.

¹Splits expenditure of those services which serve both adults and children - 60% children and 40% adults. This is based on the proportion of clients at the largest service serving both adults and children - the Kogarah Development and Assessment Service.

Table 4 - Specialised intellectual disability health services - estimated expenditure and staffing (FTE), 2008-09 by AHS

AHS	Staffing (FTE)	Expenditure (\$m)
SESI	19.1	2.170
SSW	26.6	3.361
SW	8.6	1.251
NSCC	incomplete	incomplete
HNE	12.9	1.382
NC	0	0
GW	0	0
GS	5.8	0.483
CHW	27.0	3.272
Other ¹	1.4	0.039
Total	101.4	11.958

Source: NSW Health survey of existing specialised intellectual disability health services, provided to KPMG by NSW Health in August 2009.

¹Developmental Disability Health Unit

A list of existing specialised services for people with intellectual disability currently is outlined in Appendix A.

Demand for specialised intellectual disability health services

There is limited data relating to the numbers of people with an intellectual disability in NSW and Australia. The best estimate is provided by the Australian Bureau of Statistics' Survey of Disability, Ageing and Carers (2003), which estimates that approximately 2.5 per cent of people aged 0-64 in NSW have an intellectual disability (equivalent to approximately 123,500 people).¹⁴ The Commonwealth-State/Territory Disability Agreement (CSTDA) Minimum Data Set indicates that in 2006-07, there were 28,000 people in NSW with intellectual disability (0.4 per cent of the total population) in receipt of disability support services at sometime during the year.¹⁵

The target group for direct services by specialised intellectual disability health services are those people with an intellectual disability (or developmental delay) *and* complex health needs. There is no prevalence data available relating to intellectual disability and complex health conditions: determining the level of demand for specialised services is difficult. However, it has been suggested¹⁶ that approximately 0.2 per cent of the population of NSW - or 15,000 people - are within the target group for specialised services, that is, have an intellectual disability and complex health needs. This figure is unable to be verified, however.

¹⁴ ABS (2004): Survey of Disability, Ageing and Carers, 2003

¹⁵ Australian Institute of Health and Welfare, *Interactive Disability Data*, http://d01.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/Disabilities/all_20067

¹⁶ Centre for Education and Research on Ageing Concord Hospital: Developmental Disability Database. Extrapolation from health status data on 500 adults with Intellectual Disability. Personal correspondence A/Prof Lynette Lee

Many people with intellectual disability could potentially benefit from specialised services as they seek to increase the capacity of mainstream health services to meet the health needs of people with intellectual disability.

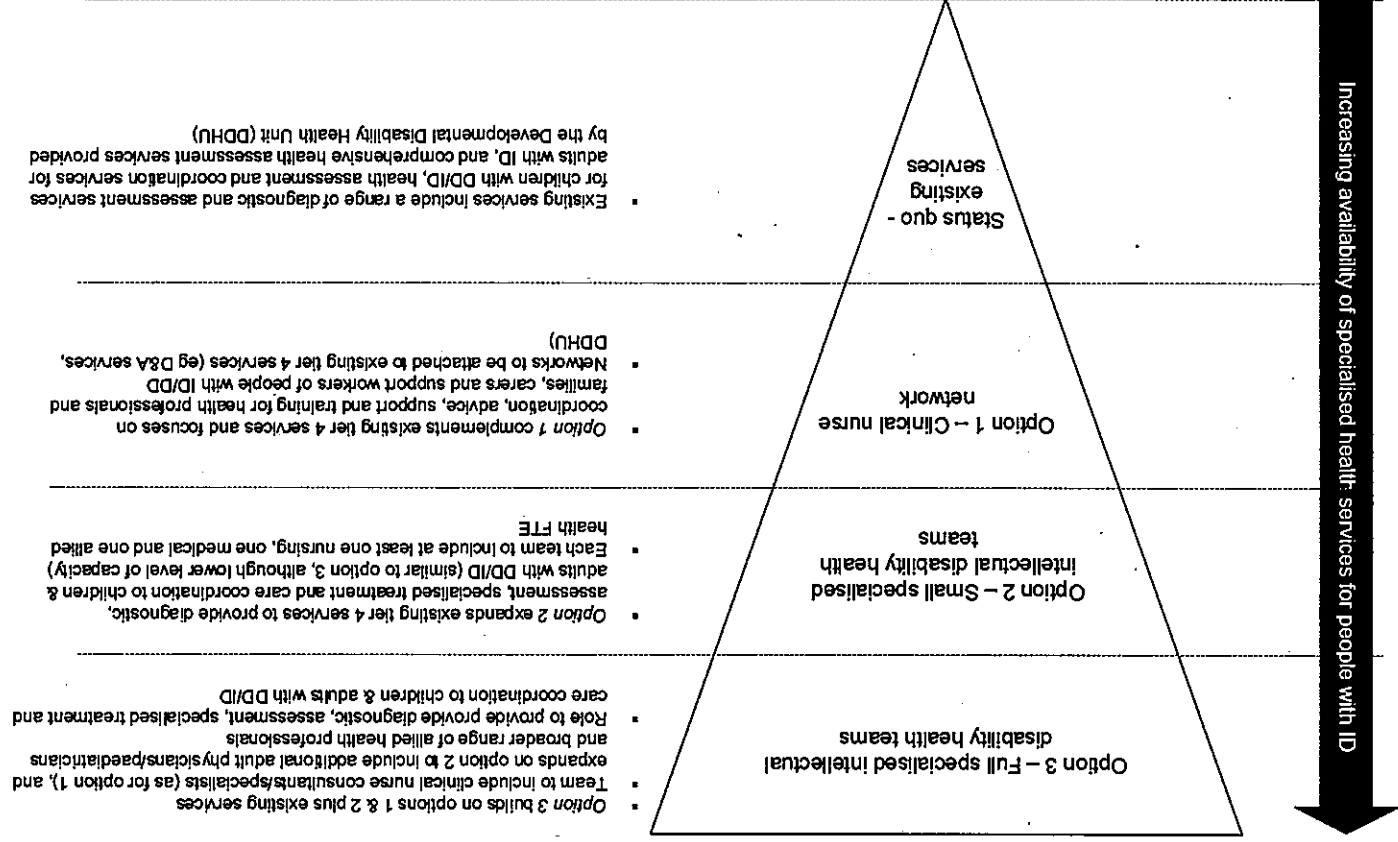
Options for further developing specialised intellectual disability health services

There were three options proposed for specialised intellectual disability health services in the draft Framework:

- Option 1 - Clinical nurse network
- Option 2 - Small intellectual disability health teams
- Option 3 - Full intellectual disability health teams

Each of the options proposed is intended to build on existing specialised services, and represent an increasing level and intensity of specialised services for people with intellectual disability. An overview of options is outlined in the diagram below, followed by further description of each option.

Figure 1 - Overview of tier four options¹⁷



¹⁷ developed by KPMG

Option 1 - Clinical nurse network

This option involves establishing a network of specialised intellectual disability nurses - Clinical Nurse Consultants (CNCs) and Clinical Nurse Specialists¹⁸ (CNSs) - across the state to work with people with intellectual disability, their families and carers, and clinicians - to plan and coordinate services and facilitate service pathways for people with intellectual disability through the health system, and/or to provide education, training and liaison for clinicians treating people with intellectual disability.

There are two sub options:

- 1a. A network of CNCs to work with health professionals and disability support staff; and
- 1b. A network of CNCs and CNSs to work with health professionals and disability support staff and people with an ID, their families and carers.

Option 1a: A network of CNCs

This sub-option, proposes nine CNCs strategically located across the state who will work with a range of health professionals who provide health services to people with intellectual disability as well as disability and other support workers, to increase their capacity to respond to the health needs of people with intellectual disability and to ultimately improve the care and support that health professionals are able to provide to people with intellectual disability.

The role of a CNC is well established in the NSW health system, and CNCs exist in many different nursing specialties and health services. The role of the CNC - in general - is to:

- provide expert clinical advice to patients, carers and other health care professionals within a defined speciality. The Clinical Nurse Consultant develops, facilitates implementation and evaluates care management plans for patients with complex health needs
- provide leadership that facilitates the ongoing development of clinical practice.
- initiate and utilise findings of research in the provision of clinical services
- contribute to the development and delivery of specialty related education programs.
- participate in formal processes for the strategic and operational planning for the clinical service. The role also involves the organisation and delivery of specialist consultant service.

An intellectual disability CNC would focus on:

- *Facilitating high quality health promotion and care for individuals with complex needs* - provide consultation, nursing assessment and care planning for people with intellectual disability and complex health care needs.
- *Advice and liaison* - provide advice to health professionals working with people with intellectual disability, including advice on particular health conditions or needs of people with intellectual disability, and how to respond to their needs (for example, referral advice, effective treatments), and advice on how to work with people with intellectual disability and their families, carers and support workers.
- *Education, training and capacity building* - provide education and training to health professionals to increase their capacity to respond to the health needs of people with intellectual disability.

¹⁸ Reference is made to CNSs however it is acknowledged that initially these roles will be filled by experienced Registered Nurses with an intention of providing development and training opportunities for these nurses to become CNSs. The supply of CNSs will be an issue which will be addressed in a workforce development strategy.

- *Facilitating networks* - facilitate networks of health professionals who work with people with intellectual disability to provide collegial support and facilitate the sharing of knowledge, learnings and experiences.

Number of nursing positions

Under this sub-option, it is proposed that there be one CNC per AHS - nine CNCs in total. Each CNC will work across their Area,

The number of full-time equivalent positions proposed per AHS is outlined below:

Table 5 - Number of full-time equivalent positions per AHS (option 1a)

AHS	SESI	SSW	SW	NSCC	HNE	NC	GW	GS	CHW	Total
CNCs (FTE)	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	9.0

Source: Number of positions as proposed and agreed to by the Framework Advisory Group.

Option 1b: A network of CNCs and CNSs

Under this sub-option, nine CNCs (as for option 1a), are complemented with 23 clinical nurse specialists (CNSs) who will work with clinicians as well as people with an intellectual disability, their families, carers and support workers.

As for CNCs, the role of a CNS is also well-established in the NSW health system. Their role is to apply a high level of clinical nursing knowledge, experience and skills in providing complex nursing/midwifery care directed towards a specific area of practice, a defined population or defined service area, with minimum direct supervision¹⁹.

CNS is a personal grading which is earned by an experienced 8th year Registered Nurse who has obtained relevant post-registration qualifications, and meets a range of criteria around clinical practice, mentoring and professional development.

Under this sub-option, the CNC would undertake their role as described in option 1a (health promotion and care, advice and liaison, education, training and capacity building, and facilitating networks) with CNSs supporting the CNCs in this role, as well as providing more direct support to people with intellectual disability, their families, carers and support workers. In particular, the role of an intellectual disability CNS will be to provide:

- *Clinical care* - provide complex care requiring advanced clinical skills, and primary case management of clients with intellectual disability and complex health care needs.
- *Advice and liaison* - provide advice to health professionals working with a people with intellectual disability, including advice on particular health conditions or needs of people with intellectual disability, and how to respond to their needs (for example, referral advice, effective treatments), and advice on how to work with people with intellectual disability and their families, carers and support workers.
- *Planning* - work with health professionals to assist in the development of health care plans for people with intellectual disability, and assist with monitoring of plans.
- *Coordination and facilitation* - coordinate a range of health professionals and health services that individuals with intellectual disability may access or need to access, including facilitating appropriate pathways to services. CNSs may work directly with individuals, their families,

¹⁹ NSW Health. Public Health System Nurses' and Midwives' (State) Award 2008. Accessed at <http://www.health.nsw.gov.au/resources/jobs/conditions/awards/nurses.asp>

carers and support workers in this coordination and facilitation role, and/or work with other health professionals to assist them coordinate services and facilitate appropriate pathways.

Number of nursing positions

Under this option, it is proposed that there will be two nursing (CNC/CNS) positions per 450,000 people,²⁰ including one CNC per AHS, with the remaining positions in each AHS being CNSs. Each CNC will work across their Area, and CNSs will work either across their Area or within specific networks or localities within their Area (as determined by individual Areas).

The number of full-time equivalent positions per AHS proposed is outlined below:

Table 6 - Number of full-time equivalent positions per AHS (option 1b)

AHS	SESI	SSW	SW	NSCC	HNE	NC	GW	GS	CHW	Total
CNCs (FTE)	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0	9.0
CNSs (FTE)	4.4	5.2	4.1	4.1	2.8	1.2	0.3	1.2	0.0	23.3
Total	5.4	6.2	5.1	5.1	3.8	2.2	1.3	2.2	1.0	32.3

<i>Population (2009 est.)*</i>	1.21m	1.40m	1.15m	1.14m	0.87m	0.50m	0.30m	0.49m	na	7.05m
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Source: Number of positions determined by AHS population and allocation per 450,000 - as proposed and agreed to by the Framework Advisory Group.

* provided by NSW Health

Note that these positions (for both sub-options 1a and 1b) represent *additional positions* - over and above nursing and other staff working in existing specialised intellectual disability health services.

The nursing positions would be attached to existing specialised services operating in Areas. For those Areas where no specialised services exist currently, nursing positions could be located within Department of Rehabilitation Medicine or Paediatrics (or other Departments as determined by individual AHSs, in consultation with NSW Health) and supported by existing specialised services in other Areas.

Benefits of a clinical nurse network

The main benefits of a clinical nurse network, as outlined in the Framework and by the Framework Advisory Group, are:

- better coordination for clinical services for people with intellectual disability
- enhanced focus on and capacity for the promotion of healthy lifestyles and prevention of chronic disease in people with intellectual disability
- increased capacity of health professionals and disability support professionals to meet the health and care needs of people with intellectual disability - through the provision of clinical leadership to RNs who work with people with intellectual disability, and advice and support to other clinicians
- increased level of assistance and support to families and carers of people with intellectual disability - particularly around health management issues.

²⁰ Note that this ratio was proposed and agreed to by the Framework Advisory Group, and reflects the Advisory Group's view on the number of nursing positions required to serve a population catchment area with 450,000 people - using the Kogarah/Sutherland area (and Kogarah Developmental Assessment Service) as an example.

As for all specialised services, this option is intended to contribute to better health outcomes for people with intellectual disability.

The main differences between the benefits provided by option 1a (CNC network) and option 1b (CNC/CNS network) are related to the *capacity* of the network to provide assistance to people with intellectual disability and their families and carers. Option 1b allows for a greater focus on coordination of services for people with intellectual disability and their families and carers, and allows more people to be assisted. Given the limited number of proposed CNCs under option 1a, their ability to work with people with intellectual disability and their families and carers will be very limited. Further, option 1b provides a greater level of capacity to provide advice and support to clinicians, families and carers around treatment and health management strategies, and creates additional capacity for health promotion activities.

Option 2 – Small intellectual disability health teams

This option involves establishing small, multidisciplinary teams comprising nursing, medical and allied health professional to provide specialised multidisciplinary and comprehensive diagnosis, assessment, and clinical services to adults and children with intellectual disability or developmental delay and complex health needs, provide support and have a capacity building role for other clinicians who may work with children and adults with intellectual disability or developmental delay.

The role of intellectual disability health teams will be to:

- *Diagnosis and assessment* - provide diagnoses of conditions leading to intellectual disability and assessments of functional abilities, providing comprehensive health assessments for people with intellectual disability, and development of health care plans.
- *Investigation and testing* - undertake investigative procedures and testing to determine nature of health conditions, and liaise with and refer to medical specialists for further diagnosis and treatment of particular health conditions (including, for example, gastroenterology, orthopaedics).
- *Treatment and management* - providing treatment and management of specific health conditions experienced by individuals with an intellectual disability, including consultation with acute hospitals to prevent avoidable hospitalisation, and providing advice and support to families, carers and support workers of people with intellectual disability relating to the day-to-day management of specific health conditions (e.g. medication management).
- *Coordination and facilitation* - coordinate a range of health professionals and health services that individuals with intellectual disability may access or need to access, including performing a case coordination role.
- *Supporting other clinicians* - providing advice to other health professionals working with people with intellectual disability, including advice on treatments for and management of particular health conditions, how to respond to their needs (for example, referral advice, effective treatments), and advice on how to work with people with intellectual disability and their families, carers and support workers.
- *Education, training and capacity building* - provide direct clinical education and training to health professionals to increase their capacity to respond to the health needs of people with intellectual disability.
- *Data collection* - implementing systems for the collection of clinical and service data to facilitate evaluation and research.

This option builds on option 1b - the clinical nurse (CNC and CNS) network - by incorporating nursing, allied health and medical professionals.

Size of intellectual disability health teams

Under this option, it is proposed that there be:²¹

- two nursing FTE positions per 450,000 people, including one CNC per AHS with the remaining positions in each AHS being CNSs (as for option 1b above, and reflecting the fact that this option builds upon option 1b);
- two medical FTE positions per 450,000 people, including a developmental paediatrician, adult physician and/or other staff specialist (combining to a total of two FTEs), with specific specialties to be determined by individual AHSs.
- one allied health FTE position per 450,000 people, which could be a psychologist, social worker, physiotherapist, occupational therapist, dietician or speech therapist (or mix of disciplines combining to a total of one FTE)

The number of full-time equivalent positions per AHS proposed is outlined below:

Table 7 - Number of full-time equivalent positions per AHS (option 2)

AHS	SESI	SSW	SW	NSCC	HNE	NC	GW	GS	CHW	Total
Nursing - CNC/CNS	5.4	6.2	5.1	5.1	3.8	2.2	1.3	2.2	1.0	32.3
Medical	5.4	6.2	5.1	5.1	3.8	2.2	1.3	2.2	2.0	33.3
Allied health	2.7	3.1	2.5	2.5	1.9	1.1	0.7	1.1	1.0	16.7
Director - medical	One medical director per Area - one of medical FTEs as outlined above (ie no add'l FTE); cost will be Director's loading only									
Total	13.5	15.5	12.7	12.7	9.5	5.5	3.3	5.5	4.0	82.3

<i>Population (2009 est.)*</i>	1.21m	1.40m	1.15m	1.14m	0.87m	0.50m	0.30m	0.49m	na	7.05m
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Source: Number of positions determined by AHS population and allocation per 450,000 - as proposed and agreed to by the Framework Advisory Group.

* provided by NSW Health

Note that the table above represents the total positions per Area, rather than additional positions. While the total cost of this option based on the number of positions proposed above is relatively straightforward to determine (and is outlined in the next section), the net cost of this option, and the distribution of resources and positions to Areas where there is insufficient services currently, depends on robust data relating to existing staff numbers, resourcing and their distribution (both distribution across the State and distribution across the lifespan).

Given most resources are currently allocated to services for children in metropolitan areas, any additional resources will likely be used to provide services to adults, and to adults and children in non-metropolitan areas. For this reason, it is assumed that only some of the existing resources

²¹ Note that the FTE/population ratio used in this (and other) options was proposed and agreed to by the Framework Advisory Group, and reflects the Advisory Group's view on the number of positions required to serve a population catchment area with 450,000 people - using the Kogarah/Sutherland area (and Kogarah Developmental Assessment Service) as an example.

currently used for specialised services - and in particular only resources used to deliver services to adults - can be used to offset the cost of this option.

At this stage only estimates exist on the level of resources currently allocated to specialised intellectual disability health services (including services for adults), which means the level of additional resources is difficult to determine. This is discussed further in the section 4.

Benefits of a specialised intellectual disability health team

The main benefits of specialised intellectual disability health teams, as outlined in the Framework and by the Framework Advisory Group, are:

- the promotion of a patient-centred approach rather than a discipline-oriented approach to diagnosis and treatment of people with intellectual disability
- the provision of comprehensive assessment and consultation service in a way that is "seamless" for patients
- enhanced focus on and capacity for the promotion of healthy lifestyles and prevention of chronic disease in people with intellectual disability.
- enhanced early and accurate diagnosis of conditions, thereby reducing chronic disease and acute illness.
- reduced hospitalisations and more effective and cost efficient hospitalisations.
- increased capacity of health professionals and disability support professionals to meet the health and care needs of people with intellectual disability
- increased level of assistance and support to families and carers of people with intellectual disability - particularly around health management issues
- facilitation of treatment planning, streamlining of referral processes and prevention of unnecessary duplication of investigations, thus saving time and resources
- the centralisation of expertise that allows better communication and coordination between different professions and between services and the provision of support to other clinicians
- reduced disability service support needs flowing from avoidable illnesses or conditions

Option 3 - Large intellectual disability health teams

This option involves building on the small, multidisciplinary teams established under option 2 to provide additional, specialised multidisciplinary and comprehensive diagnosis, assessment, and clinical services to adults and children with intellectual disability or developmental delay who have complex health needs, and to provide support and have a capacity building role for other clinicians who may work with children and adults with intellectual disability or developmental delay.

Under this option, the number of health professionals working within specialised teams is significantly more than under option 2, allowing for a greater level and intensity of service to be provided to people with an intellectual disability (allowing for more patients to be assisted and/or patients to receive a more intensive level of service), and a greater level of liaison and support for other clinicians.

Size of intellectual disability health teams

Under this option, it is proposed that there be:

- two nursing FTE positions per 450,000 people, including one CNC per AHS with the remaining positions in each AHS being CNSs (as for option 1b and 2 above);
- 5.5 medical FTE positions per 450,000 people, including a developmental paediatrician, developmental psychiatrist, adult physician and/or other staff specialist(s), as well as 1.5 trainee FTE, with specific specialties to be determined by individual AHSs.
- 8.0 allied health FTE position per 450,000 people, which could be a psychologist, social worker, physiotherapist, occupational therapist, dietician, and/or speech therapists, with specific disciplines to be determined by individual AHSs.
- a Medical Director in each Area
- 3.0 administration officer FTE per 450,000 people.

The number of full-time equivalent positions per AHS proposed is outlined below:

Table 8 - Number of full-time equivalent positions per AHS (option 3)

AHS	SESI	SSW	SW	NCCC	HNE	NC	GW	GS	CHW	Total
Nursing - CNC/CNS	5.4	6.2	5.1	5.1	3.8	2.2	1.3	2.2	1.0	32.3
Medical	14.8	17.2	14.0	13.9	10.6	6.1	3.7	5.9	3.0	89.1
Allied health	21.5	25.0	20.4	20.2	15.4	8.9	5.4	8.6	3.0	128.3
Director - medical	One medical director per Area - one of medical FTEs as outlined above (ie no add'l FTE); cost will be Director's loading only									
Admin	8.1	9.4	7.6	7.6	5.8	3.3	2.0	3.2	1.0	48.0
Total	49.8	57.7	47.1	46.7	35.6	20.5	12.4	19.9	8.0	297.8

<i>Population (2009 est.)*</i>	1.21m	1.40m	1.15m	1.14m	0.87m	0.50m	0.30m	0.49m	na	7.05m
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Source: Number of positions determined by AHS population and allocation per 450,000 - as agreed to by Framework Advisory Group.

* provided by NSW Health

The table above represents the total positions per Area, rather than additional positions. The net cost of this option, and the number of additional positions, depends on robust data relating to existing staff numbers, resourcing and its distribution. At this stage only estimates exist on the number of staff and resources allocated to specialised intellectual disability health services, which means determining the number of additional positions and resources, and distribution of these additional positions and resources across Areas, difficult to determine. This is discussed further in the next section.

Benefits of a specialised intellectual disability health team

As noted under option 2, there are a number of benefits of specialised intellectual disability health teams.²² The greater the number of health professionals, the greater the potential to provide a fully integrated, comprehensive health care service to people with intellectual disability, and assist more people with intellectual disability, ultimately leading to better health outcomes for people with intellectual disability. As such, the level of benefit provided by full specialised intellectual disability health teams would be greater than that provided under option 2.

²² as outlined in the Framework and by the Framework Advisory Group,

Project management and evaluation

As part of the implementation of specialised intellectual disability health services, there will also likely be a need for additional resources for project and implementation management, evaluation, and data collection for service delivery and outcomes monitoring - as discussed by NSW Health and the Framework Advisory Group. The purpose and estimated level of additional resources required for each of these components is outlined below, and have been included in the costings presented in section 4:

- Project and implementation management within NSW Health, to oversee the planning and implementation of the options. This will include development of service descriptions and position descriptions, liaison with AHSs during planning and implementation phases, monitoring and reporting of progress. As discussed with NSW Health and the Framework Advisory Group, it is proposed that an additional Senior Policy Officer (grade 9/10) position be created within the Primary Health and Community Partnerships Branch within the NSW Department of Health to undertake this project and implementation management role. It is proposed that this role be established for six months (or 0.5 FTE over a year), commencing in 2011-12 (first year of proposed implementation).
- Conduct an impact evaluation to assess the impacts or benefits of the initiative - including impacts on the health and health outcomes of people with an intellectual disability, on the health and quality of life of families and carers, and the impacts on the health system and disability service system more broadly. The results of the evaluation can be used to inform a business case for option 3 - full intellectual disability health teams.
- Development of a consistent, statewide data collection system for intellectual disability health services. Consistent and robust data is necessary for monitoring service delivery, including levels of service, service access and availability, and efficiency, as well as ongoing monitoring of service effectiveness or outcomes. In addition, the development of a statewide data collection system will provide a rich source of data to inform any impact evaluation of the initiatives.

4 Specialised intellectual disability health services – costs and benefits

Introduction

This section provides a summary of the estimated costs of each of the three options for specialised intellectual disability health services outlined in the previous section, and provides a description of the benefits of each option.

Estimated costs

There are two main groups who will bear the cost of implementing each of the options relating to specialised intellectual disability health services: the NSW Government and the Australian Government.

NSW Government (NSW Health)

Additional costs borne by the NSW Government will relate to:

- staff costs (salaries, salary on-costs, leave entitlements, training and development)
- other non-staff operating expenses (facility costs, equipment/depreciation, medical consumables)
- establishment costs (such as building refurbishment, information technology, project management)

The direct cost to the NSW Government will be offset by two sources: Medicare revenue (discussed below), and the level of resources already allocated to existing services.

There may also be other, less direct costs associated with the options proposed. It is likely that, through increased detection and diagnosis of health conditions among people with an intellectual disability, that there may be increased costs relating to treatment and management of those conditions - particularly in universal health services. However, this will obviously lead to better health outcomes for people with intellectual disability, and potentially reductions in health care costs in future years as more acute and chronic interventions are avoided.

Australian Government – Medicare rebates

Services are able to claim Medicare rebates for some ambulatory care services provided by doctors (staff specialists)²³, which represents a cost to the Australian Government, though a benefit (revenue) to the NSW health system. However, It should be noted that AHSSs may not allocate Medicare revenue to the individual services that generate this revenue.

Other groups

It is unlikely that people with intellectual disability, their families and carers will bear any of the cost of specialised health services, given these services are generally delivered free of charge (that is, there are no patient fees, copayments or 'gap' charges). For the purposes of costing each option, it has been assumed that no patient fees will be charged.

²³ Rebates may be able to be claimed by other health professionals - such as psychologists - though this is not current practice and therefore have not been incorporated into the modelling.

Existing resources (cost offset)

As noted earlier, total NSW Health expenditure on specialised services is estimated to be \$12.0 million in 2008-09 - based on a survey of AHSs undertaken by NSW Health in mid-2009.²⁴

To some extent the level of existing resources will offset the cost of some of the options for specialised intellectual disability health services - in particular option 2 and option 3, should this be implemented (the cost of option 1 will not be offset by existing resources, given it has been assumed that clinical nurse positions are new positions).

However, existing resources are concentrated in metropolitan areas, and the majority of resources are used to provide services for children, with few services for adults with intellectual disability. Option 2, in particular, will focus on filling these gaps, and it is likely that any additional funding will be used to provide specialised health services to adults with intellectual disability. For this reason, it has been assumed that only those existing resources used to provide services to adults will offset the cost of option 2 (that is, \$1.837 million, as outlined in table 3)

The full teams proposed under option 3 will provide services across the lifespan, and will incorporate existing services to adults and children. For this reason, it has been assumed that all existing resources will offset the cost of option 3 (that is, \$11.958 million).

Annual recurrent costs estimates

The table below outlines the estimated annual costs of each of the options proposed, in 2009-10 dollars:

Table 9 - Estimated annual costs of tier four options

	Option 1a - CNC network	Option 1b - CNC/CNS network	Option 2 - Small ID health teams	Option 3 - Full ID health teams
Estimated cost per annum ¹	1.364	4.575	19.013	52.561
Estimated Medicare revenue per annum ²	0	0	2.688	5.295
Estimated net cost per annum	1.364	4.575	16.325	47.267
Current funding (2008-09) ³	na	na	1.837	10.121
Estimated funding required per annum	1.364	4.575	14.488	37.146

Source: KPMG

Amounts expressed in 2009-10 dollars. Future years' costs will increase by the level of cost escalation.

¹This represents the total recurrent cost of each option to the NSW Government. Costs include all staff costs and estimated non-staff operating costs per position, and include: salary costs, superannuation (9 per cent), workers compensation (2 per cent), and an allocation for general operating expenses per position (37 per cent) - as advised by NSW Health, and representing the NSW Health standardised costing method. Costing assumptions are outlined in Appendix B.

²Assumptions relating to the calculation of Medicare revenue are outlined in Appendix B. Note that while Medicare revenue is a benefit for the NSW health system, AHSs may not allocate this revenue to the individual services that generate this revenue.

³Note that these figures were collated through a survey of AHSs undertaken by NSW Health in 2009, and represent the best estimate of the level of funding allocated to specialised intellectual disability health services currently. For option 2, only those existing resources used to provide services to adults will offset the cost; for option 3, all existing resources will offset the cost. The accuracy of these figures have not been able to be verified by KPMG.

Infrastructure costs

Additional physical and other infrastructure will likely be required to establish specialised intellectual disability health services. This will include:

²⁴ However, this is likely to be an underestimate of the total cost of providing services, given it is likely some costs (such as some overhead costs covered by AHSs centrally) have not been included. Further, data from some services was not submitted as part of the survey and hence has not been included.

- suitable premises or buildings, and the costs of redeveloping or refurbishing these premises;
- IT and other office equipment;
- medical equipment; and
- furniture and fittings.

It is difficult to determine likely costs of the physical infrastructure required to establish specialised intellectual disability health service. Additional physical and other infrastructure costs will be dependent on the degree to which existing infrastructure is available (for example, whether a clinical nurse consultant can utilise a space within an existing service, or will require an office to be refurbished, whether a service can be housed in an existing building requiring minimal refurbishment), IT and other office equipment already available, medical equipment already available etc. Further, infrastructure costs will also be dependent on the number of locations that services will be established.

However, some high-level cost estimates of establishing specialised intellectual disability health services have been developed - based on the following assumptions:

- Building redevelopment/refurbishment costs of \$2000 per square metre, and an allocation of 20 square metres per FTE position (including office and clinical spaces).
- IT and other office equipment and furniture and fittings of \$5,000 per FTE position.

The estimated cost of medical equipment has not been included at this stage, and will require expert clinical input to determine the equipment required and detailed cost information relating to equipment costs. However, given the nature of specialised health services, it is not expected that costly medical equipment will be required, hence the cost is unlikely to be significant.

Table 10 - Estimated establishment costs of tier four options

		Option 1a CNC network	Option 1b CNC/CNS network	Option 2 Small ID teams	Option 3 Full ID teams
Building refurbishment	\$2000/m ² 20m ² per FTE	0.360	1.293	3.293	11.910
IT, office equipment and furniture/fittings	\$5,000 per FTE	0.045	0.162	0.412	1.489
Medical equipment	tba		to be determined		
Estimated establishment costs		0.405	1.455	3.704¹	13.399²

Source: KPMG

¹Represents total establishment cost for option 2. However, if option 1b is implemented first, the additional establishment costs are estimated to be \$2.249m (= \$3.704m less \$1.455m).

²Represents total establishment cost for option 3. However, if option 2 is implemented first, the additional establishment costs are estimated to be \$9.695m (= \$13.399 less \$3.704m).

Note that these amounts do not take into account the availability of existing infrastructure utilised by existing services.

Illustrating benefits

There are a number of models of specialised health services for people with intellectual disability in place in NSW, around Australia, and internationally. Around Australia these include multidisciplinary Diagnostic and Assessment Services for children, expanded multidisciplinary Diagnostic and Assessment Services that provide a greater range of services across the lifespan and are integrated into acute and community health service; and Disability Health Units that provide clinical services, clinical leadership, research and teaching functions.

In the UK, Community Learning Disability Nurses (CLDNs) provide high-quality specialised expertise, support people to access universal services and have health promotion, health facilitation and teaching and service development roles. Health Facilitation Teams work directly with clinicians and patients, supporting care delivery and providing advice, and have a role in raising the profile of the support available to adults with intellectual disability through community teams and specialised services.

While descriptions of these services are available, no evidence or data as to the efficacy of these services has been found in research literature or from formal evaluations. Because of this lack of data, the quantification of benefits of options for specialised intellectual disability health services in NSW has not been able to be undertaken.

A 'case study' approach has been undertaken to illustrate benefits. The case studies relate to examples of clients who have or could have benefited from specific interventions, and illustrate the benefits or potential benefits of that intervention for that individual. Where possible, the benefits and costs of the intervention - as it relates to the individual - have been estimated. The case studies illustrate that, in addition to the potential improvements in health and quality of life of people with intellectual disability accessing specialised services, that there are potentially significant financial savings or benefits for the NSW Government in terms of avoided hospital costs, and in some cases, avoided costs of additional disability supports.

Summary case studies for five individuals are outlined below. Full case studies are outlined in Appendix C. It should be noted that the case study approach does not represent a true 'economic appraisal', however. Further, any quantification of the net benefits of specialised intellectual disability health services as a whole cannot be taken to represent likely net benefit, and have been presented for illustrative purposes only.

Case study 1

Christine is a middle-aged woman with intellectual disability. She lives in a group home with 24-hour support and supervision. Christine has no speech, although uses a few signs to communicate. She has a history of chest infections, bowel obstructions and anxiety.

Christine was recently admitted to a regional hospital on a Monday with diarrhoea and vomiting, including vomiting whole food that she had eaten a number of days before. A bowel obstruction was diagnosed and a nasogastric tube was inserted to drain Christine's stomach. Her guardian and group home staff warned the hospital that she would not understand or tolerate the tube and suggested sedation. No action was taken. Christine pulled out the tube, aspirated much of the contents and contracted severe aspiration pneumonia.

She was moved to intensive care in a major hospital and spent four weeks in intensive care - mostly on a ventilator. Early in the period she spent in intensive care, Christine also had surgery for bowel obstruction, and recovered quickly.

Following her stay in intensive care, Christine was moved to a high dependency ward where she spent a further three weeks recovering from the pneumonia, and an additional three weeks in an ordinary ward. In total, Christine spent 10 weeks in hospital. The pneumonia that Christine developed left her with chronic lung disease, which requires ongoing treatment and management and puts her at increased risk of further hospitalisation.

If a specialised intellectual disability health team had existed at the hospital where Christine was admitted, they would likely have established protocols for treatment and management of patients with intellectual disability, and the clinicians treating Christine may have been more aware of the needs of people with intellectual disability. The team would also have been available to provide direct advice, support and liaison to the clinicians treating Christine. The protocols, advice and support would have reinforced Christine's guardian and group home staff's advice that Christine would not tolerate the nasogastric tube, she would likely not have pulled out the tube and not developed pneumonia. Potentially, Christine would have spent a relatively short period in hospital recovering from the bowel obstruction surgery, rather than the ten weeks she did spend in hospital.

Costs and benefits

The cost of a specialised intellectual disability health services for Christine would have been relatively minimal, relative to benefits that the team could have realised in terms of avoided hospitalisation:

Intellectual disability health team advice and liaison ²⁵	\$1,000
Total potential costs - ID team intervention	\$1,000
Avoided costs:	
avoided hospital admission (6 weeks) ²⁶	\$52,300
Total estimated avoided costs	\$52,300
Comparing the actual costs incurred of an intellectual disability health team intervention for Christine with the avoided costs shows that following financial benefit to the NSW Government:	
Estimated financial benefit to NSW Government	\$51,300

This does not include non-financial benefits, including improvements to Christine's health and quality of life, nor does it include the potential future cost of managing Christine's chronic lung disease.

²⁵ Based on a 2 physician hours at a cost per hour of \$321/hr; and 3 CNC hours at a cost of \$135/hr (costs per hour includes all salary, other staff, and non-staff related costs; based on availability for 25 hours of patient-related time per week, 45 weeks per year).

²⁶ Based on an average cost per day in NSW public hospital of \$1,245 in 2007-08. Source: *National Hospital Cost Data Collection Cost Report Round 12 (2007-08) - NSW Public Sector*. Accessed from [http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/\\$File/22_NSWES_t.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/$File/22_NSWES_t.pdf)

Case study 2

Nikolas is 14 years of age and lives with his parents in inner western Sydney. Nikolas has severe intellectual disability and Autism Spectrum Disorder, as well as hyperactivity, cyclic mood disorder, and sensory processing problems. Nikolas needs assistance with self-care skills, is entirely non-verbal and requires 1:1 attention to keep him occupied and to manage his high level of activity and to prevent/manage self-injurious and Pica behaviours.

Nikolas lives with his family - his mother, father, brother and paternal grandmother. Nicholas is a twin and his brother Peter also has autism and severe intellectual disability. Misbehaviour in either boy causes distress to the other leading to impossible levels of disturbance of both self injury and aggression. Night time disturbance means that their father sleeps with one of the boys most nights and gets minimal sleep.

The effects of sustained high levels of stress on this family are enormous and there are concerns regarding their mental health. Nikolas' father, in particular, has struggled of late and has been diagnosed with depression and has revealed thoughts of harming his sons and himself.

Nikolas has a local GP who has been supportive and actively engaged with the family for several years. In addition to the range of disability supports, Nikolas utilises several specialist health staff through a specialised intellectual disability health team, with health practitioners working collaboratively with disability support staff and Nikolas' family. Health professionals involved in his care include a paediatric psychiatrist, paediatrician, cross-cultural clinical consultant, clinical psychologist, and family therapist. When hospital admission is required (even for specialist investigation and assessment), the specialised team liaises with nursing and medical staff to ensure they are aware of Nikolas' care needs and priority required to avoid an adverse incident in hospital.

Specialist expertise in psychotropics for behavioural management has been critical for managing Nikolas' behaviour, and enabling the family to cope. The importance of a specialised service has also enabled management of Nikolas' condition to be community- rather than hospital-based. Addressing and integrating the family's psychological needs with the coordination of community-based disability supports has also been a focus of case management and care coordination, with the specialised team working together with disability supports. Without such management and coordination, a likely consequence is family breakdown, leaving a situation where neither parent can provide the care that is needed, leading to additional formal supports for the family and a long-term accommodation placement for the person with intellectual disability. The main financial benefit therefore is the savings from delaying or preventing long-term care.

Costs and benefits

The cost of a specialised intellectual disability health services for Nikolas is relatively minimal, relative to the potential avoided costs:

access to intellectual disability health team ²⁷	\$10,000
Total estimated costs - ID team intervention	\$10,000
Avoided costs (per annum):	
long-term supported accommodation in a group home or in alternative family placement ²⁸	up to \$161,000
Reduced reliance of centre-based respite ²⁹	\$10,500
Reduced reliance on behaviour intervention and behaviour support ³⁰	\$6,400
Total estimated avoided costs	up to \$177,900
Comparing the actual costs incurred of an intellectual disability health team intervention for Nikolas with the avoided costs shows that there is a potential significant financial benefit:	
Estimated financial benefit to NSW Government	up to \$167,900

This does not include non-financial benefits, including maintaining the family unit and managing, improving parents' psychological health and wellbeing, reducing stress and depression, and significantly lowering the risk of harm to themselves and to Nikolas. Even if Nikolas was able to remain in the care of his family and not be placed in a group home or alternative family placement, there is still a positive estimated net financial benefit to the NSW Government of approximately \$5,000 per annum.

²⁷ Based on a cost per hour of \$321/hr (medical); \$135/hr nursing (CNC); and \$104/hr psychologist - which includes all salary, other staff, and non-staff related costs.

²⁸ ADHC-provided community living place, 2008-09 (Source: ADHC).

²⁹ The cost of an ADHC-provided respite was \$21,000 in 2008-09 (Source: ADHC). Assumes specialist intervention reduces need for respite by 50 per cent.

³⁰ Based on cost per client for ADHC-provided therapy and prevention of approximately \$6,400 in 2008-09 (Source: ADHC). Cost per behaviour intervention/behaviour support client may be higher due to the more intensive nature of services.

Case study 3

William is 14 years old and lives with his mother in the Sydney metropolitan area. William has moderate to severe intellectual disability, autistic disorder, and a number of mental issues - the most serious of which is Intermittent Explosive Disorder (a behavioural disorder characterized by extreme expressions of anger and sometimes uncontrollable rage). William is mobile and is able to feed himself, though has no speech and needs assistance with other activities of daily living. William requires constant supervision.

William was initially assessed at a specialised intellectual disability health team when he was two years old. He was found to have speech delay, socialisation/ behavioural problems, a Global Developmental Delay and was diagnosed as having Autism. William also has a history of obstructive sleep apnoea, coeliac disease, rhinitis and otitis media, and has had a dystonic (adverse) reaction to medication for which he was recently admitted to hospital.

William has been a patient of a specialised intellectual disability health service since his initial diagnosis at two years old. The current focus of the Service includes stabilising his mental health and behaviour, supporting his mother and stabilising her mental health, ensuring stability so that he can access his educational facility, and coordinating a range of health and disability supports including respite care, behavioural support through specialist Psychology Services, and speech pathology and occupational therapy. William and his mother access a Psychiatrist, Developmental Paediatrician and Social Worker, and have also seen a Neurologist and Sleep Physician.

He has been placed on psychotropic medication and has been monitored closely. New protocols have been developed regarding his presentation to the Emergency Department at a local Hospital. During the last few years, he has had a number of presentations to the ED, and has been admitted only once because of an adverse reaction to medication. Constant monitoring, support and supervision have prevented these multiple presentations evolving into hospital admissions.

Protocols and policies have been developed at the local Hospital relating to the presentation and management of people with intellectual disability in the hospital setting, and these protocols have ensured William's (and others) smooth and rapid movement through ED and return home. With the introduction of these protocols, presentations at the ED by those with an intellectual disability are flagged and support for the ED staff is provided by the Service.

The situation for William if he were unable to access an intellectual disability health team such as the specialised intellectual disability health service can be illustrated by the situation at his local hospital. If he were to present to his local hospital ED when he is distressed or unwell, he is likely to remain in the ED for a longer period of time than if a team existed, advice able to be provided, and treatment protocols established. This would likely further distress William and his family, amplifying his challenging behaviour, and increasing the likelihood that he would be admitted. The support, advice and assistance to hospital staff that could be provided by an intellectual health team would not be available, potentially resulting in sub-optimal treatment and management and significantly more lengthy stays in hospital.

Costs and benefits

The cost of a specialised intellectual disability health services for William is relatively minimal:

access to intellectual disability health team ³¹	\$6,100
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Total estimated costs - ID team intervention	\$6,100
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Avoided costs for William from having a specialised team (per annum):

avoided hospital admission, reduced length of stay ³²	\$12,500
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Total estimated avoided costs	\$12,500
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Comparing the actual costs incurred of an intellectual disability health team intervention for William with the avoided costs shows that following financial benefit to the NSW Government:

Estimated financial benefit to NSW Government	\$6,400
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This does not include non-financial benefits, including improvements to William's health and quality of life, and that of his family.

³¹Based on a 1.5 physician hours and 2 social worker hours per month, plus 20 per cent additional time for administration and reporting. Cost per hour of \$321/hr (medical) and \$103/hr (social worker) - which includes all salary and non-staff costs.

³²Based on an average cost per day in NSW public hospital of \$1,245 in 2007-08. Source: *National Hospital Cost Data Collection Cost Report Round 12 (2007-08) - NSW Public Sector*. Accessed from [http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/\\$File/22_NSWES_t.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/$File/22_NSWES_t.pdf)

Case study 4

Elizabeth is 24 years old and lives in metropolitan Sydney. She has mild intellectual disability, Prader Willi Syndrome, extremely challenging behaviour and generalised anxiety disorder. While Elizabeth has a mild intellectual disability, globally and adaptively she is extremely impaired. While she has some independent living skills, she requires assistance with eating, and some aspects of personal care.

Elizabeth had global developmental delay, feeding difficulties and hyptonia in early childhood, obesity associated with insatiable appetite, obstructive sleep apnoea and type 2 diabetes. Elizabeth has a history of oppositional and defiant behaviour, stubbornness with emotional dysregulation, self-injurious and occasionally assaultive and violent behaviour.

Elizabeth was admitted to hospital because of unstable diabetes in October 2003. However, her behaviour precluded her discharge to either her family home or to a group home, leaving no option other than remaining in hospital. Elizabeth's stay in hospital required one-to-one supervision, surveillance and care because of her challenging behaviour.

Elizabeth remained in hospital for eight months until a specialised intellectual disability health service assumed overall management and care in mid-2004. The Service provided ongoing medical care, a suitable medication regimen was established, and Elizabeth was referred to a Sleep Physician for assessment. In addition, the Service engaged DADHC and a group home place found and therapy and behaviour management support provided, and the Public Guardian was engaged. The Service's intervention and its coordination of services and supports allowed Elizabeth to be discharged from hospital.

Elizabeth subsequently moved out of the area and was lost to follow up.

Costs and benefits

The cost of a specialised intellectual disability health services and disability supports for Elizabeth, compared with the avoided costs, are:

access to intellectual disability health team ³³	\$5,200
disability supports (group home, therapy and behaviour management) ³⁴	\$167,400
Total estimated costs	\$172,600
Avoided costs:	
avoided hospital admission (240 days) ³⁵	\$300,000
Total estimated avoided costs	\$300,000
Comparing the actual costs incurred of an intellectual disability health team intervention for Elizabeth with the avoided costs shows that following financial benefit to the NSW Government:	
Estimated financial benefit to NSW Government	\$127,400
This does not include non-financial benefits, including improvements to Elizabeth's health and quality of life.	

³³ Based on a 10 physician hours at a cost per hour of \$321/hr; and 10 CNC hours at a cost of \$135/hr, plus an additional 20 per cent non patient-facing time. Costs per hour include all salary, other staff, and non-staff related costs.

³⁴ Based on the cost of an ADHC-provided community living place of approximately \$161,000 and cost per client for ADHC-provided therapy and prevention of \$6,400. All figures relate to 2008-09 (Source: ADHC).

³⁵ Based on an average cost per day in NSW public hospital of \$1,245 in 2007-08. Source: *National Hospital Cost Data Collection Cost Report Round 12 (2007-08) - NSW Public Sector*. Accessed from [http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/\\$File/22_NSWEst.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/$File/22_NSWEst.pdf)

Case study 5

Helen is a 41 year old woman with mild cerebral palsy and intellectual disability. She lives in a group home and is in supported employment. Helen has had 3 fractures in the last 4 years that have resulted from falls. One of these fractures was that of her hip and this required internal fixation (surgery). Subsequently, Helen developed arthritis in that hip and she has now had hip replacement. Helen also has a history of seizures in early childhood, but has not had any seizures for 40 years. However, she continues to taken an anticonvulsant medication.

Helen was referred to a specialised intellectual disability health team for a comprehensive health assessment. On taking a full medical history, it was noted that Helen had never menstruated. Further investigations showed that Helen had hypogonadism (low oestrogen) and osteoporosis resulting from her hypogonadism. She was treated for her hypogonadism and osteoporosis. After neurological review, her anticonvulsant therapy was ceased. She continues to be seizure free. Helen had a vision assessment and new glasses were prescribed. Her falls have since reduced.

Helen's fractures, surgery for the broken hip and subsequent hip replacement have incurred considerable health care costs. Early assessment by an intellectual disability health team would have identified her hypogonadism and osteoporosis, and identified a need for neurological review and review of her anticonvulsant medication. The costs of this early intervention would have been relatively minor relative to the costs actually incurred.

Costs and benefits

The cost of specialised intellectual disability health services, compared with the avoided costs, are:

access to intellectual disability health team ³⁶	\$2,600
neurologist consultation ³⁷	\$400
Total estimated costs	\$3,000
Avoidable costs:	
Avoided hospital admission and surgery (internal hip fixation, hip replacement) (21 days) ³⁸	\$26,150
Avoided rehabilitation ³⁹	\$6,250
Total estimated avoidable costs	\$32,400
Estimated financial benefit to NSW Government	\$29,400

This does not include non-financial benefits, including improvements to Helen's health, quality of life or lost productivity.

³⁶ Based on a 6 physician hours (two sessions at three hours each) at a cost per hour of \$321/hr; and 2 social worker hours at a cost of \$103/hr, plus an additional 20 per cent non patient-facing time. Costs per hour include all salary, other staff, and non-staff related costs.

³⁷ Based on one-hour consultation plus 20 per cent reporting time, at a cost of \$321/hr. Costs per hour include all salary, other staff, and non-staff related costs.

³⁸ Based on an average cost per day in NSW public hospital of \$1,245 in 2007-08. Source: *National Hospital Cost Data Collection Cost Report Round 12 (2007-08) - NSW Public Sector*. Accessed from [http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/\\$File/22_NSWEs1.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/0BF59B7DB88A427FCA257609001FCD3D/$File/22_NSWEs1.pdf)

³⁹ Based on 2 hours per week of physiotherapy for six months (three months for internal hip fixation, three months for hip replacement), plus an additional 20 per cent non patient-facing time - at a cost per hour of \$100/hr (physiotherapist). Cost includes all salary, other staff, and non-staff related costs.

The case studies are reflective of client experiences and offer some value in illustrating the benefits of specialised intervention.

If the benefits described above were 'typical' of the benefits that would accrue to the client population accessing the service, an illustrative assessment of the relative cost effectiveness of the options proposed can be provided - based on the illustrative numbers of clients accessing services offered by each option. The following table illustrates the net financial benefit to the NSW Government based on the *most conservative* estimate of benefit from the case studies above (that is, from case study 3).

Table 11 - Illustrative costs and benefits of intellectual disability health teams

	Estimated total cost ¹	No. of clients (illustrative) ²	Estimated financial benefit ³	Net financial benefit	Benefit-cost ratio
Small ID teams (option 2)	\$19.013m	2971	\$37.135m	\$18.122m	2.0
Large ID teams (option 3)	\$52.561m	8213	\$102.658m	\$50.097m	2.0

Source: KPMG

¹Based on the total estimated annual recurrent cost of each option.

²Based on the total estimated cost of each option and the average annual cost of specialised intellectual disability health services per client of \$6,400, as indicated in case study 3.

³Based on the indicative financial savings/benefit from case study 3 of \$12,500 per client.

Implementation of options

Each of the options for tier 4 services can also be seen as 'stages' of development of intellectual disability health services in NSW - with a greater level and availability of service provided to people with intellectual disability as each of the options is implemented. However, while a clinical nurse network (option 1) is effectively the first stage of development, by itself such a network is unlikely to have a major impact on health outcomes for people with intellectual disability and as such merely lays the 'groundwork' for small intellectual disability health teams (option 2), and in the long-term, larger intellectual disability health teams (option 3).

There are two options for staged implementation of specialised intellectual disability health services:

- *Implementation option 1* - In the short term, the clinical nurse network (option 1b) is established with nurse positions in each AHS. Building on this network and existing services, small intellectual disability health teams are then established in each AHS. In the long-term, small intellectual disability health teams (option 2) will be expanded to larger teams (option 3).

The advantage of this option is that it builds specialised services gradually, and allows each stage to be evaluated before the next stage is implemented and allows for service provision and outcomes data to be collected over time (to contribute to evaluation). More importantly, it allows for the necessary workforce to be developed to implement full intellectual disability health teams over time. However, the main disadvantage is that it delays the implementation of intellectual disability health teams, which are likely to deliver the most benefit for people with intellectual disability.

- *Implementation option 2* - rather than establishing the clinical nurse network as the first stage, instead small intellectual disability health teams could be established in each AHS, focussing initially on those AHS with no or few services. In the long-term, small intellectual disability health teams (option 2) can be expanded to larger teams (option 3). However, it is important that a sufficient body of evidence to support the efficacy of intellectual disability health teams be collected first before small teams are implemented. This option would also mean that clinical

nurses can be located within a specialised intellectual disability health service, rather than operating independent of a service (as would be the case in the short term under implementation option 1).

Implementation option 2 allows for small intellectual disability health teams to be implemented sooner than under implementation option 1. Implementation option 2 also means that clinical nurses can be located within a specialised intellectual disability health service, rather than operating independently of a service (as would be the case in the short term under implementation option 1), which will increase the effectiveness of the clinical nurses as they work as part of a multidisciplinary team. Therefore, based on the available evidence, implementation option 2 will mean that greater benefits can be realised for people with intellectual disability - at least in the short term - and a likely greater net benefit overall is likely to be realised.

The following table outlines the total recurrent funding required over the next five years, assuming the phasing suggested under implementation option 2.⁴⁰

Table 12 - Estimated recurrent cost of implementing tier four options

\$m	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
1. CNC/CNS network	0	0	0	0	0	0
2. Small ID health teams	0	14.488	14.488	14.488	14.488	14.488
Total	0.000	14.488	14.488	14.488	14.488	14.488

Source: KPMG

Note that all amounts are expressed in 2009-10 dollars, and do not take account of any future cost escalation.

*Subject to a separate business case.

The following table outlines the total estimated infrastructure (one-off) funding required for implementation.

Table 13 - One-off funding required for implementing tier four options

\$m	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
1b. CNC/CNS network	0	0	0	0	0	0
2. Small ID health teams	0	3.704	0	0	0	0

Source: KPMG

Costs include building refurbishment costs, and IT, office equipment and furniture/fittings. Do not include cost of medical equipment.

Note that these amounts do not take into account the availability of existing infrastructure utilised by services currently in place.

Project management and evaluation costs

As part of the implementation of specialised intellectual disability health services, there will also be a need for:

- *Project and implementation management* within NSW Health - 0.5 FTE Senior Policy Officer (employed at grade 9/10 - level 10 maximum), employed for one year in 2011-12 (first year of proposed implementation).
- *Evaluation* - \$150,000 to evaluate the effectiveness and impact of small intellectual disability health teams in 2013-14, and used to inform a business case for full intellectual disability health teams.
- *Development of a statewide data collection system* for intellectual disability health services. It is difficult to estimate the cost of developing a statewide data collection system, given such a system will depend on the level and nature of data to be collected, the platform on which the

⁴⁰ It has been assumed that the first year of implementation will be 2011-12 to give time for NSW Health to secure funding for the initiative. The timing of implementation is a matter for NSW Health to determine, however.

data collection system is based, existing data collection systems which may be able to accommodate data collection relating to intellectual disability health services (for example, through modification), existing IT infrastructure and ability of this infrastructure to maintain a data collection system, and need for additional data collection support staff. As such, no firm estimate can be provided on the estimated cost of developing a data collection system without further investigation of data collection needs and status of existing systems and infrastructure. This should be investigated further by NSW Health's Information Management branch, in conjunction with the proposed GMCT (tier 5) service.

The estimated cost of project management and evaluation is outlined in the table below:

Table 14 - Estimated cost of project management and evaluation

\$m	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
Project management	0	0.140	0	0	0	0
Evaluation	0	0	0	0.150	0	0
Data collection			to be determined			
Total	0	0.140	0	0.150	0	0

Source: KPMG

Note that all amounts are expressed in 2009-10 dollars, and do not take account of any future cost escalation.

5 Clinical leadership, research, education and training

Introduction

This section outlines the options, costs and benefits relating to tier 5 of the Framework - clinical leadership, research and education and training.

Need for intellectual disability health clinical leadership, research, education and training

The role of tier 5 is to provide an oversight and leadership role for health services and health professionals working with people with intellectual disability, coordinating the development of services (and underlying systems), influencing and having input into the training and education of health professionals working with people with intellectual disability, shaping the research agenda and activities relating to intellectual disability health services.

This coordination and leadership function is necessary to ensure that both universal and specialised services are available and responsive to the needs of people with intellectual disability, that sufficient capacity exists in the health system to respond to the health needs of people with intellectual disability, and to promote evidence-based practice to ensure health outcomes for people with an intellectual disability improve.

Currently, there are a range of leaders and specialist intellectual disability health practitioners in NSW, providing a range of clinical services, research, training and health professional development and education. However, these activities are not well-coordinated, and there is no high-level leadership oversighting these activities. Unlike many other health areas and disciplines, there is no clinical network for intellectual disability health to guide service development or systems development, there is no dedicated intellectual disability health leadership to guide research or education, and no comprehensive and coordinated research plan or agenda at a State level.

Further, there are a number of academics in NSW who have a research interest and undertake research in various aspects of intellectual disability,⁴¹ and a Centre for Disability Studies (CDS) which conducts a number of research projects relating to disability more broadly. In addition, a new Chair in Intellectual Disability and Mental Health has recently been established at UNSW and funded by DHS (encompassing the former DADHC), to focus on research and education in this field, in recognition of the fact that many people with intellectual disability are at higher risk of having a psychiatric disorder or mental health issues and that their access to mental health services is sometimes limited. However, there are no university chairs in Intellectual Disability Medicine, Intellectual Disability Nursing, or in Intellectual Disability Allied Health (or specific allied health discipline) to provide leadership in research for the broader intellectual disability health sector and in university-level and clinical education for medical professionals, nurses, or allied health professionals.

Components

There are two components proposed to develop intellectual disability health clinical leadership, research, education and training in NSW:

⁴¹ Including, for example, Prof Gwynnyth Llewellyn in Families and Parenting, Prof Stewart Einfeld in Epidemiology, Prof Susan Hayes in Criminal Justice, Dr Ellie Smith in Genetics, Prof Perminder Sachdev in Neuropsychiatry, A/Prof Lynette Lee in Ageing, A/Prof Roger Stancliffe in Support, and Dr Linda Goddard in Health Mentoring.

- Development of a clinical network within the Greater Metropolitan Clinical Taskforce (GMCT) to provide support and clinical leadership to health professionals working with people with intellectual disability, coordinate the development of intellectual disability health services, and to provide input into research, education and training.
- Establishment of three professorial chairs of intellectual disability medicine, nursing, and allied health, linked to clinical services and faculties of medicine, nursing and allied health at appropriate universities.

These options are complementary rather than mutually exclusive, and are each described further below:⁴²

1. Intellectual disability health clinical network

The GMCT was established within NSW Health to promote clinician and consumer involvement in planning and health service delivery. There are 20 clinical networks which operate within GMCT, including networks relating to aged care, renal services, strokes services, and transition care. Each network seeks to identify how and where improvements can be made to service delivery, and promotes and facilitates the implementation of improvements within the health system. Each network is coordinated by a network manager, and involves a range of health professionals, researchers, managers and consumers.⁴³

Agreement has already been reached on the establishment of an intellectual disability health clinical network within GMCT. The role of this network - similar to the role of other networks - will likely include:

- identify improvements in intellectual disability health service delivery, and develop specific initiatives to implement change (for example, standardised treatment protocols, models of care, service benchmarks)
- facilitate education and training for health professionals working with people with intellectual disability, particularly to support early intervention and prevention
- facilitate the development of data collection systems to provide health professionals with data to guide clinical practice and provide comprehensive, comparable data relating to service provision and outcomes
- facilitate clinical research and the dissemination of results through links with existing disability research facilities and university research centres

The network will require network support staff, including:

- 1.0 FTE network manager - employed at Health Service Manager 4 (HSM4) to coordinate the activities and projects undertaken by the network
- 1.5 FTE project officers to support the network manager and undertake additional research and development activities - employed at HSM2

This level of resourcing is similar to other networks, though larger networks have additional support staff.

Benefits

The main benefits of the network will to coordinate intellectual disability health service provision and to guide service and clinical improvements in the intellectual disability health service sector - improving the effectiveness of service delivery and ultimately health outcomes for people with intellectual disability.

⁴² Options are those discussed and agreed to by NSW Health and the Framework Advisory Group

⁴³ Sourced from <http://www.health.nsw.gov.au/gmct/>.

As with other GMCT networks, it will be clinician-led, with clinicians working collaboratively together to identify and implement improvements.

2. University Chairs in intellectual disability medicine, nursing and allied health

It is proposed that three professorial Chairs of Intellectual Disability Medicine, Nursing, and Allied Health be established to provide leadership in research and education in these fields. Chairs would be located within faculties of medicine, nursing and allied health at a leading NSW university or universities, and would maintain strong links with clinical services - including specialised intellectual disability health teams and clinical nurse networks - clinical research undertaken at tertiary-level hospitals, and clinical education.

In particular, the role of the Chairs would be to:

- facilitate the development and delivery of university education (undergraduate and postgraduate) and clinical education and training in their respective fields
- lead the development of a research program in relation to intellectual disability health in their respective fields
- contribute to the development of intellectual disability health services, linking with specialised teams and clinical nurse networks
- providing leadership and input into the GMCT network for intellectual disability health
- assisting in building the community of practitioners with expertise in intellectual disability health.

Benefits

The main benefits of this option will be to:

- Improve the education and training of health professionals so that they have increased knowledge and capacity to work with people with intellectual disability, and increase the number of health professionals with sufficient training to provide specialised intellectual disability health services
- Increase and better coordinate research in intellectual disability health, leading to a broader evidence base underpinning service delivery
- Improve the effectiveness of service delivery as a result of increased knowledge and capacity of health professionals and a greater evidence base for clinical practice
- Ultimately contribute to improving health outcomes for people with intellectual disability

Workforce development

A key component of both tier 5 options will be a focus on the development of a health workforce sufficiently trained and equipped to work with people with an intellectual disability, and in particular to provide the specialised health services described in tier 4 of the Framework. Currently, there are workforce shortages in a number of health professional disciplines within the NSW public health system generally, and this is projected to worsen. Added to this is the current lack of sufficiently experienced practitioners in intellectual disability health, again something which will worsen as workforce shortages become more significant.

Without concerted effort to develop a health workforce sufficiently trained and equipped to work with people with an intellectual disability and provide specialised intellectual disability health services, the effectiveness of any of the options proposed under tier 4, and the Framework generally, may not be guaranteed. In particular, without additional workforce development efforts

full specialised intellectual disability health teams (option 3 for tier 4 services) is unlikely to be able to be implemented.

Both the proposed GMCT Intellectual Disability Health Network and Chairs in Intellectual Disability Medicine, Nursing and Allied Health, together with NSW Health, should work collaboratively to address both the development of the capacity of health professionals in universal services to work with people with intellectual disability, and the development of a specialised intellectual disability health workforce.

Estimated costs

1. GMCT Network

The estimated cost of the GMCT intellectual disability health network is based on the following:

- 1.0 FTE network manager employed at Health Service Manager 4 (HSM4) - at a salary of \$117,985 per annum, plus 11 per cent on-costs (9% superannuation and 2% workers compensation), and an allocation of 25% of estimated total costs for non-staff operating costs
- 1.5 FTE project officers employed at HSM2 level - at a salary of \$75,720 per annum, plus 11 per cent on-costs (9% superannuation and 2% workers compensation), and an allocation of 25% of estimated total costs for non-staff operating costs

2. University Chairs

DHS (encompassing the former DADHC) provide funding to UNSW for a professorial Chair in Intellectual Disability and Mental Health. DHS advise that \$2.1 million will be provided to UNSW over five years - or approximately \$420,000 per annum. It has been assumed that any professorial chairs in intellectual disability medicine, nursing and allied health would be funded at the same level. Funding includes provision for an academic position, research and administrative support and non-staff related costs.

The estimated annual recurrent cost of a GMCT network and university chairs are outlined in the table below:

Table 15 - Estimated recurrent cost of tier five components

\$m	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
GMCT network	0	0.287	0.287	0.287	0.287	0.287
University chairs (x3)	0	1.260	1.260	1.260	1.260	1.260
Total	0	1.547	1.547	1.547	1.547	1.547

Source: KPMG

Note that all amounts are expressed in 2009-10 dollars, and do not take account of any future cost escalation.

Summary

The purpose of tier 5 is to provide an oversight and leadership role for health services and health professionals working with people with intellectual disability, coordinating the development of services (and underlying systems), influencing and having input into the training and education of health professionals working with people with intellectual disability, shaping the research agenda and activities relating to intellectual disability health services.

The two proposed components for tier 5 to achieve this are the establishment of a GMCT network for intellectual disability health, and the establishment of three university chairs in intellectual disability medicine, nursing and allied health.

It is estimated that the cost of these two components will be \$1.547 million per annum.

6 Summary and key findings

Tier 4 services

A number of options for expanding and enhancing specialised intellectual disability health services have been considered. These are:

1. Establishment of a Clinical Nurse network across Area Health Services.
2. Establishment of small, specialised, multidisciplinary health teams across Area Health Services to provide specialised health services to people with intellectual disability, building on existing specialised services.
3. Establishment of larger, specialised, multidisciplinary health teams across Area Health Services to provide comprehensive, specialised health services to children, adolescents and adults with intellectual disability, building on existing specialised services

Ultimately, specialised intellectual disability health services will contribute to improving the health status and health outcomes for people with intellectual disability, as well as the quality of life of people with intellectual disability and their families and carers. Specialised intellectual disability health services also have the potential to lead to real savings in health service and disability support costs through more intensive, earlier intervention, earlier diagnosis and detection of conditions, and more effective management and treatment, and avoiding more costly health and disability interventions as health conditions progress. Further, specialised services will provide:

- better coordination for clinical services for people with intellectual disability
- enhanced focus on and capacity for the promotion of healthy lifestyles and prevention of chronic disease in people with intellectual disability.
- promotion of a patient-centred approach rather than a discipline-oriented approach to diagnosis and treatment of people with intellectual disability
- provision of comprehensive assessment and consultation service in a way that is "seamless" for patients
- increased capacity of health professionals and disability support professionals to meet the health and care needs of people with intellectual disability
- increased level of assistance and support to families and carers of people with intellectual disability - particularly around health management issues
- facilitation of treatment planning, streamlining of referral processes and prevention of unnecessary duplication of investigations, thus saving time and resources
- the centralisation of expertise that allows better communication and coordination between different professions and between services and the provision of support to other clinicians.

It is estimated that the cost of implementing tier 4 services are as follows:

Table 16 - Estimated cost of implementing tier four options

\$m	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
<i>Tier 4¹</i>						
1. Clinical nurse network	0	0	0	0	0	0
2. Small ID health teams	0	14.488	14.488	14.488	14.488	14.488
3. Full ID health teams	0	0	0	0	0*	0*
Project mgmt & evaluation	0	0.140	0	0.150	0	0
Physical infrastructure	0	3.704	0	0	0	0
Total - tier 4	0	18.332	14.488	14.638	14.488	14.488

Source: KPMG

Note that all amounts are expressed in 2009-10 dollars, and do not take account of any future cost escalation.

¹Assumes implementation of small intellectual disability health teams in the short term (implementation option 2), rather than implementation of the CNC/CNS network (implementation option 1).

*Does not include funding required to implement full intellectual disability health services. This will be subject to the evaluation of small teams and the development of a separate business case, following evaluation of small teams.

Tier 5 services

Two components for enhancing and clinical leadership, education, training and research have also been considered. These are:

1. Establishment of a clinical network to provide support and clinical leadership to health professionals working with people with intellectual disability, coordinate the development of intellectual disability health services, and to provide input into research, education and training
2. Establishment of three professorial chairs of intellectual disability medicine, intellectual disability nursing, and intellectual disability and allied health, linked to clinical services and faculties of medicine, nursing and allied health at appropriate universities.

Investment in clinical leadership, research and education through a GMCT network and university Chairs in intellectual disability health will:

- improve the education and training of health professionals so that they have increased knowledge and capacity to work with people with intellectual disability, and increase the number of health professionals with sufficient training to provide specialised intellectual disability health services
- increase and better coordinate research in intellectual disability health, leading to a broader evidence base underpinning service delivery
- improve the effectiveness of service delivery as a result of increased knowledge and capacity of health professionals and a greater evidence base for clinical practice
- ultimately contribute to improving the health status and health outcomes for people with intellectual disability, as well as the quality of life of people with intellectual disability and their families and carers.

It is estimated that the cost of implementing tier 5 services are as follows:

Table 17 - Estimated cost of implementing tier five components

\$m	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16
<i>Tier 5</i>						
1. GMCT network	0	0.287	0.287	0.287	0.287	0.287
2. University chairs	0	1.260	1.260	1.260	1.260	1.260
Total - tier 5	0	1.547	1.547	1.547	1.547	1.547

Source: KPMG

Note that all amounts are expressed in 2009-10 dollars, and do not take account of any future cost escalation.

Key findings

There is insufficient quantitative data and evidence to conduct a robust economic appraisal of the range of Framework options in the absence of a minimum State-wide data set on the costs, service activity and performance of existing services available to people with intellectual disability or evaluation data on individual services.

However, based on available evidence and consultation, small multi-disciplinary intellectual disability health teams are likely to provide the highest net benefit in terms of cost effectively delivering improved health outcomes for people with intellectual disability.

The recurrent cost of implementing small intellectual disability health teams is estimated to be \$14.488 million per annum, net of Medicare revenue and existing resources allocated to specialised services for adults with intellectual disability.

The anticipated benefits of small multi-disciplinary teams include better coordination of health services for people with intellectual disability, more intensive, earlier intervention, earlier diagnosis and detection of conditions, and more effective management and treatment. These benefits are also likely to result in avoided costs associated with early intervention.

There are workforce issues which will constrain the implementation of intellectual disability health teams in the short term, and additional costs are likely to be incurred as a result of any workforce development activities, including provision of training and education and financial and non-financial incentives. These costs have not been quantified.⁴⁴

There is a need for additional, Statewide clinical leadership, and for improved coordination of education and training and research activities in the area of intellectual disability health. The appraisal suggests this can be best achieved through a GMCT-like network for intellectual disability health and University Chairs in Intellectual Disability Medicine, Nursing and Allied Health.

⁴⁴ However, the costs of ongoing training and professional development for staff employed in specialised intellectual disability health services have been included in the recurrent cost estimates for operating these services.

7 Appendices

- A Specialised intellectual disability health services - current service provision
- B Costing assumptions
- C Illustrating benefits - case studies

A Specialised intellectual disability health services - current service provision

Table A1 - No of specialised intellectual disability health services for children and adults (reported by AHSs), 2009

AHS	Children	Adult	Both	Total
SESI	1	1	1	3
SSW	3	1	1	5
SW	3	0	3	6
NSCC	2	0	0	2
HNE	1	0	0	1
NC	0	0	0	0
GW	0	0	0	0
GS	1	1	0	2
CHW	5	0	1	6
DDHU	0	1	0	1
Total	16	7	3	26

Source: NSW Health survey of existing specialised intellectual disability health services in July 2009. Collated survey data provided to KPMG by NSW Health in August 2009.

Table A2 - Specialised intellectual disability health services - expenditure and staffing (FTE) (reported by AHSs), 2009

AHS	Staffing (FTE)	Expenditure (\$m)
SESI	19.1	2.170
SSW	26.6	3.361
SW	8.6	1.251
NSCC	incomplete	incomplete
HNE	12.9	1.382
NC	0	0
GW	0	0
GS	5.8	0.483
CHW	27.0	3.272
Other ¹	1.4	0.039
Total	101.4	11.958

Source: NSW Health survey of existing specialised intellectual disability health services in July 2009. Collated survey data provided to KPMG by NSW Health in August 2009.

Table A3 - Specialised intellectual disability health services in NSW

AHS	Service
SSWAHS	Department of Community Paediatrics, Liverpool
	Child Assessment Team, Campbelltown
	Child, Adult & Family Team, Bankstown
	Dept Rehabilitation Medicine, Concord Hospital - Developmental Disability Clinic at Concord Hospital and Adult Clinics at DSU (Burwood)
	SSWAHS Mental Health Intellectual Disability Service
CHW	PECAT
	Department of Psychological Medicine, Children's Hospital at Westmead
	Child Development Unit, Children's Hospital at Westmead
	Dysphagia Nutrition Clinic, Children's Hospital Westmead
	Bone Health Multi-discipline Clinic for Children with Cerebral Palsy
SWAHS	Disability Specialist Unit
	Blue Mountains Child & Adolescent Development Unit
	Growth and Development Clinic, Nepean
	General Disability Clinic - Westmead Campus
	Westmead Campus - Dysphagia Nutrition Clinic
SESIAHS	Westmead Campus- Complex Epilepsy/Developmental Disability Clinic
	Auburn Child Development Clinic
	Kogarah Developmental Assessment Service SESIAHS, Developmental Disability Network (incl. Illawarra Diagnosis & Assessment Service)
NSCCAHS	Tumbatin Developmental Assessment Clinic, SCH
	CANDID (Clinic for Assessment of Neuropsychiatric Disorders in Intellectual Disability)
GSAHS	NSCCAHS Child & Family Health Central Coast CHAT
	Speech Pathology Central Coast
	Chatswood D&A*
HNEAHS	Dr Davis, Goulburn
	Child, Infant and Family Tertiary Service (CIFTS)
NCAHS	Child and Family Health Team - Kaleidoscope
NCAHS	no services
GWAHS	no services
Statewide	Developmental Disability Health Unit

Source: NSW Health survey of existing specialised intellectual disability health services in July 2009. Collated survey data provided to KPMG by NSW Health in August 2009.

* no data received, so not included in expenditure, staffing, or service figures presented in this report.

B Costing assumptions

Cost per FTE position - specialised intellectual disability health services

The following FTE cost assumptions were used in estimating the cost of each option for specialised intellectual disability health services.

Costs are based on the NSW Health standardised method for determining the cost of additional positions and the 2008-09 costs provided to KPMG by the Department. Costs per FTE include:

- salary costs (as per relevant NSW Health Award)
- on-costs - superannuation (9 per cent), workers compensation (2 per cent)
- an allocation for general operating expenses per position (37 per cent).

2008-09 costs have been escalated by 3.9 per cent to reflect salary and other cost increases.

Table B1 - Cost per FTE

Classification	Cost per FTE - 2008-09	Cost escalation - 08-09 to 09-10	Cost per FTE - 2009-10
8 th year Registered Nurse	\$102,895	3.9%	\$106,908
CNS	\$132,496	3.9%	\$137,663
CNC	\$145,830	3.9%	\$151,517
Social worker	\$112,066	3.9%	\$116,437
Psychologist	\$113,074	3.9%	\$117,484
Physiotherapist	\$108,499	3.9%	\$112,730
OT	\$106,663	3.9%	\$110,823
Speech pathologist	\$105,408	3.9%	\$109,519
Dietician	\$113,087	3.9%	\$117,497
Developmental Paediatrician	\$347,227	3.9%	\$360,769
(Developmental) Psychiatrist	\$347,227	3.9%	\$360,769
Physician	\$347,227	3.9%	\$360,769
Other specialist	\$347,227	3.9%	\$360,769
Dentist (dental specialist)	\$242,268	3.9%	\$251,716
Trainees (Registrars)	\$195,368	3.9%	\$202,987
Administration	\$88,014	3.9%	\$91,447
Director (loading) ¹			\$50,850

Source: NSW Health

Cost per FTE position included all staff costs and estimated non-staff operating costs per position, and include: salary costs, superannuation (9 per cent), workers compensation (2 per cent), and an allocation for general operating expenses per position (37 per cent) - as advised by NSW Health, and representing the standardised method for determining the cost of additional positions. 2008-09 costs have been escalated by 3.9 per cent to reflect salary and other cost increases.

¹ Based on 2009-10 Staff specialist award, Level 3 Managerial allowance of \$45,811, plus 9 per cent superannuation and 2 per cent workers compensation (non-staff operating costs already assumed to be included in medical position FTE).

Medicare revenue – intellectual disability health services

Estimated Medicare revenue for specialised intellectual disability health services was based on the claim patterns of the Kogarah Developmental Assessment Service and the number of staff specialist FTEs making claims – as detailed in the table below. Based on the Kogarah Service, it was estimated that each staff specialist FTE will generate \$80,649 in Medicare revenue per annum.⁴⁵

Table B2 - Kogarah Developmental Assessment Service - Medicare claims, 2008

MSB item no.	MBS benefit ¹	Total claims	Revenue ²
110	115.9	32	\$3,709
116	58.0	218	\$12,644
122	140.6	3	\$422
132	202.6	289	\$58,551
133	101.45	60	\$6,087
135	202.6	58	\$11,751
291	347.5	6	\$2,085
293	217.2	4	\$869
296	199.8	49	\$9,790
304	102.2	8	\$818
306	141.05	442	\$62,344
308	163.6	54	\$8,834
336	168.7	3	\$506
338	191.51	1	\$192
350	134.35	2	\$269
822	160.2	1	\$160
823	213.5	68	\$14,518
828	167.95	43	\$7,222
858	213.5	4	\$854
Total		1345	\$201,624

No of staff specialist FTEs	2.5
Claims per FTE	\$80,649

Source: NSW Health survey of existing specialised intellectual disability health services in July 2009 – additional data provided by SESIAHS. Collated survey data provided to KPMG by NSW Health in August 2009.

¹ Based on rates from 1 January – 30 October 2008

² these figures represent claims processed; revenue received may be discounted by 5-10 %.

⁴⁵ It should be noted that some medical professionals in specialised intellectual disability health teams will not be staff specialists. In non-metro areas in particular, medical professionals may be Visiting Medical Officers (VMOs) paid by the service, and hence services will not receive Medicare revenue.