



Transition Care Workforce Project

Final Report: November 2008



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PREFACE

This is the final report of the Greater Metropolitan Clinical Taskforce (GMCT) Transition Care Workforce Project. The primary objectives of the project were to confirm the numbers of young people with chronic diseases/disabilities currently attending paediatric and adult health services, identify those transitioning to adult care, identify service gaps and determine specific medical, nursing and allied health workforce required to manage these young people in the adult health system within a multidisciplinary model.

THE INVESTIGATORS

This project was undertaken by Susan Lister in consultation with GMCT Transition Network Manager, Lynne Brodie and GMCT Transition Coordinators Lif O'Connor, Joanne Brady, Tracey Finn and Karen Johnson-Dewit.

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- Bruce Czerniec and Wendy Andrews from GMCT IT who were involved in the development of maps in this report
- GMCT Transition Diabetes Working Group
- NSW Health:
 - Chronic Care Program
 - Workforce Planning
 - Statewide Services
 - Community Health and Outpatient Care Data Collection project
- Director of Allied Health
- AHS Directors of Allied Health
- AHS Planners
- NSCCAHS Clinical Redesign Complex Chronic Care project – Annette Marley
- Institute of Medical Education and Training
- Clinical Excellence Commission
- Institute of Trauma and Injury Management
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- Diabetes Australia
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- Division of General Practice's ABHI program – Australian Better Health Initiative, Northern Sydney General Practice Network
- Sue O'Reilly, GMCT Communications Manager
- Diane Stevenson, Officer Manager GMCT

Glossary

Area Health Services (AHS)

NSCCAHS	Northern Sydney Central Coast Area Health Service
SWAHS	Sydney West Area Health Service
SWSAHS	South West Sydney Area Health Service
SESAHS	South East Sydney Illawarra Area Health Service
GSAHS	Greater Southern Area Health Service
GWAHS	Greater Western Area Health Service
HNEAHS	Hunter New England Area Health Service
NCAHS	North Coast Area Health Service
CHW	The Children's Hospital at Westmead

Hospitals

JHCH	John Hunter Children's Hospital
POW	Prince of Wales Hospital
RPAH	Royal Prince Alfred Hospital
RNS	Royal North Shore
SCH	Sydney Children's Hospital

Health professions

AH	Allied Health
RN	Registered Nurse
DE	Diabetic Educator
MO	Medical Officer
OT	Occupational Therapist
CNC	Clinical Nurse Consultant
Physio	Physiotherapist
SW	Social Worker
FTE	Full – time equivalent
CME	Continuing medical education

Diagnoses, IT and general

IMET	Institute of Medical Education and Training
CEC	Clinical Excellence Commission
CP	Cerebral Palsy
EB	Epidermolysis Bullosa
ED	Emergency Department
HOIST	Health Outcomes and Information Statistical Toolkit - NSW Health Statistical Software Tool
PAS	Patient Administration System
iPM, CIAP, CAPS, PEDD, PIMMS, CHIME, CHIS	– all Patient Administration Systems used by Area Health Services
WL	Waiting list
LOS	Length of stay
ICD-10AM	International Classification of Diseases, Revision 10, Australian Modified
ABHI	Australian Better Health Initiative
SHIP	Strategic Health Investment and Planning Committee (SWAHS)

EXECUTIVE SUMMARY

Transition in this paper refers to *the purposeful, planned movement of adolescents and young people with chronic physical and medical conditions from child-centred to an adult orientated health care system*¹.

Background

This report has been prepared for the Transition Care Network for Young People with Chronic Childhood Illnesses, an initiative of the Greater Metropolitan Clinical Taskforce (GMCT)². Preliminary investigation to explore appropriate models of care and workforce issues impacting on transition processes was undertaken by the Transition Care Network Manager and Co-ordinators from 2004-2005. A report titled *Recommendations for Service Planning for Transition in NSW*³ was sent to NSW Health in February 2006. Funding was then obtained from GMCT for the Workforce Project to look more closely at workforce and service gaps, investigate education and training issues and report the findings to NSW Health and other key stakeholders. A project officer was appointed in mid 2007 for 12 months to complete this project.

The majority of young people with chronic disease/disability such as spina bifida, diabetes and cerebral palsy, move from the three tertiary paediatric hospitals in Sydney to a wide range of adult hospitals and community care services across NSW. The increased lifespan of young people with chronic conditions, in addition to the increasing incidence of some conditions such as Type 1 diabetes in childhood, have led to more young people transitioning to adult services⁴.

Method

Preliminary work undertaken prior to the commencement of the Workforce Project identified five priority conditions comprising either a) the most prevalent clinical groups for young people requiring transition from paediatric to adult health care or b) those with special needs. A decision was made to focus on these conditions which included diabetes, other endocrine, spina bifida, gastroenterological and neurological conditions. Data was collected from:

1. Public hospital outpatient and outreach clinics via questionnaires on patient and workforce data
2. Inpatient and Emergency Department (ED) data systems
3. Key stakeholders re workforce planning and training for transition care

Results

Data was collected from a total of 156 outpatient and outreach clinics across NSW - 64 paediatric and 92 adult clinics. A total of 8768 patients with the priority conditions were identified.

Gaps in the adult workforce across all professional groups were identified. Clinicians also identified additional skills required to meet the special health concerns of young people in adult facilities.

Training shortfalls and solutions by condition

Diabetes – Type 1

Shortfalls:

- There are adequate numbers of endocrinologists in metropolitan Sydney although distribution varies and some areas such as Liverpool have service gaps. Many adult endocrinologists predominantly see patients with Type 2 diabetes.
- Most regional areas experience some degree of service shortfall but these appear to be most heightened in the Hunter and Illawarra regions.

Solutions:

- More education for GPs, allied health staff and nurses working in adult services is required for Type 1 Diabetes transition care issues.
- More Diabetes Educators are required in rural areas e.g. Dubbo, Orange, Coffs Harbour and Grafton.

Other endocrine

Solutions:

- As for Type 1 Diabetes regarding adult clinical staff.
- More education required on congenital endocrine conditions across all professional groups.

Cerebral Palsy, Spina Bifida and Developmental Disability

Shortfalls:

- There is a lack of knowledge about the needs of young people with these conditions across all professional groups in adult services
- Lack of training opportunities for all professions in adult health services including nursing e.g. disability nursing training no longer exists
- Shortage of orthotics in adult services
- Workforce issues are particularly acute for outer metropolitan services

Solutions:

- A model has recently been developed by the Statewide Spina Bifida Collaborative and submitted to NSW Health, recommending that a full time Clinical Nurse Consultant and part time Area Health professional be employed to develop, establish and coordinate a collaborative Statewide Resource Health Team for adults with spina bifida.

‘There is evidence that dedicated adult clinic services can reduce morbidity and mortality and enrich quality of life if adequately funded to support this group of patients with complex needs’²⁰

A model has also been developed by clinicians working with young people with developmental disability and submitted to NSW Health, recommending a medical registrar training position be created at Westmead Hospital. Such a position would benefit young people across a broad range of chronic illness groups.

Gastroenterology

Shortfalls:

- There are adequate numbers of gastroenterologists across most areas of greater metropolitan Sydney but access to specialists and other clinicians who are interested in managing young people is more difficult in outer metropolitan areas e.g. Gosford, Illawarra, Campbelltown and Liverpool.

Solutions:

- More services are required that are orientated to the needs of young people especially in outer metropolitan areas

Rare Genetic Conditions

Shortfalls:

- The majority of paediatric patients with rare complex genetic conditions, including rare metabolic disorders such as PKU, plus connective tissue disorders such as osteogenesis imperfecta, have traditionally been managed by the Children's Hospital at Westmead. A much smaller group has been managed at Sydney Children's (< 10 adolescents) and by specialists from this hospital running outreach clinics at John Hunter Children's Hospital.
- Approximately 50% of patients aged over 18 are still being managed in a paediatric facility and several hundred patients now require urgent transition to adult health services.
- The main workforce shortfalls include adult medical specialists and registrars, dieticians, clinical nurse specialists and administrative support. FTE have been outlined in the 2007 proposal to the SHIP Committee at SWAHS.

Solutions:

- An appropriate adult service for this cohort of young people and adults is currently being developed at Westmead Hospital. Funding issues for recurrent management will require ongoing negotiation with the three tertiary paediatric hospitals.

Epidermolysis Bullosa (EB)

- The majority of young patients with EB are currently managed at Sydney Children's Hospital (SCH). There are 36 patients attending clinics at SCH, eight of whom are aged > 18yrs. Adult patients are currently managed at St George and Prince of Wales hospitals.
- Although there are relatively small numbers of patients with EB state-wide, these young people have complex needs particularly around dressings and wound management and consultations are intensive and time-consuming.
- All patients require access to gastroenterology, pain services, haematology (for iron infusions) and plastic surgery (for removal of skin cancers). Most are on home enteral nutrition.
- Issues that need to be addressed in the development of a service model include:
 - Identification and funding of an appropriately resourced adult service that provides equity of access to multidisciplinary outpatient care
 - Funding of suitable dressings and other equipment needs
 - More nursing hours for the current part-time CNC position based at SCH

Many obstacles have been identified which impact on continuity of care and equity of access to appropriate adult health care for young people with EB. Lack of adult physicians, nursing and allied health staff with the skills to care for young people with chronic complex disorders and lack of suitable facilities for young people in adult hospitals is key issues that need to be addressed in planning service delivery, in conjunction with relevant professional bodies such as the Institute for Medical Education and Training (IMET).

Services provided to older people with chronic disease such as diabetes are often not suitable for young people transitioning from paediatric services with the result that they may not attend appointments. This can lead to an increased clinical risk that could have been avoided if suitable services were provided. There are also many cases where young people continue to be treated in paediatric hospitals due to a lack of adult services.

Recommendations:

The following recommendations have arisen from this project:

The main solutions for transition care workforce planning arising from the consultations are:

- Continuation of strategies known to be effective, such as employment of Transition Co-ordinators across the Child Health Networks and in specific key sites such as the three tertiary paediatric hospitals – suggest review after three years
- All AHSs to establish Transition Committees to identify priorities for transition and develop Area-specific strategies to meet workforce requirements
- Provision where possible of case management for young people with complex chronic illnesses such as spina bifida. There is increasing evidence that having a central person to help co-ordinate care ensures better outcomes for young people in the early period after they leave paediatric services
- Adopting a multidisciplinary approach to managing young people with chronic conditions in the adult health system and providing equity of access to appropriate services
- Increasing the proportion of appropriately skilled medical, allied health and nursing staff by re-skilling the existing workforce and training new clinical staff in transition care to meet service gaps
- Increasing the role and training of GP practice nurses, particularly in rural and regional areas of NSW
- Increasing the training and recruitment of professionals in areas of short supply e.g., rare genetic disorders, spina bifida, developmental disability and orthotics
- Addressing staff retention, succession planning and the retraining of expert staff to cover a range of health conditions
- Implementing models of care which include a single point of access and involve general practice in case co-ordination
- Promoting self-management and prevention for patients and their carers, using strategies such as telephone health coaching, focusing on the patient journey and involvement of the primary carer
- Piloting models – e.g. multidisciplinary redesign Wagner model with GP involvement in complex care
- Integration of public and private services including GPs via the Australian Better Health Initiative and Non-Government Organisations
- Identifying sources of funding for proposed models of transition care

Recommendations – education and training

- Building on existing models - Transition Coordinators continuing to provide education across all professional groups, which has a ripple effect
- Increased use of e-learning options especially for regional and rural areas
- Promotion of the 2008 GP Resource Kit (2nd edition) which includes practical advice on transition and expanding the role of practice nurses in GP surgeries to include transition planning reference GP resource kit³⁰
- Developing core competencies for staff managing young people with chronic illnesses/disabilities and providing increased skills in case management
- Encouraging young people to be more proactive in self management and documentation of their condition e.g via the NSW Health 'Red Book'
- Succession planning for clinicians about to retire
- Training ED staff to identify young people repeatedly presenting and increasing ED liaison with GPs to reduce the number of presentations e.g. using clinical protocols and electronic tracking systems for frequent presenters

Recommendations specific to IT requirements and patient clinical information systems

- All outpatient clinics need to have a user friendly electronic data collection system with consistent state-wide data items
- Establish Area Patient Administration Systems to collect consistent state-wide outpatient data items and facilitate easy extraction of reports
- Clinical and administrative outpatient clinic staff should receive regular training so they can enter data and extract reports from clinic data systems
- Explore any variations in rates of ED presentation and admission by condition using ISC and ED data (where higher than expected age-standardised admission/presentation rates by condition)

FINAL REPORT

1. Background

Transition in this paper is defined as *'the purposeful, planned movement of adolescents and young people with chronic physical and medical conditions from child-centred to an adult orientated health care system'*¹.

The workforce project was funded by the Transition Care Network for Young People with Chronic Childhood Illnesses, an initiative of the Greater Metropolitan Clinical Taskforce (GMCT)². The Transition Network commenced in 2004 and aims to:

1. Improve continuity of care between paediatric and adult care
2. Ensure appropriate and continued follow-up in the adult health care system
3. Improve support to young people with chronic disease during transfer of care

Preliminary work to explore appropriate models of transition care and workforce issues was undertaken by the Transition Care Network Manager and Co-ordinators. A report titled *Recommendations for Service Planning for Transition in NSW*³ was sent to NSW Health in February 2006. Funding was then obtained for the Workforce Project from GMCT to further investigate education and training issues and report the findings to NSW Health and other key stakeholders. A project officer was appointed in June 2007 for 12 months to complete this project.

The majority of young people with chronic disease or disability move from the three tertiary paediatric hospitals - John Hunter Children's Hospital (JHCH), Sydney Children's Hospital (SCH) and The Children's Hospital Westmead (CHW) - to a wide range of adult hospitals and community health services across NSW. The transition from a multidisciplinary, family-centred paediatric service to speciality-focused adult services is often challenging for the young person and their parents or carers.

The increased lifespan of young people with conditions such as spina bifida and cerebral palsy, in addition to the increasing incidence of conditions such as Type 1 diabetes in childhood, have led to more young people transitioning to adult services⁴.

Gaps in the adult workforce across all professions have been identified in the transition care of young people. This includes medical, nursing and allied health (AH) staff. Clinicians have also identified additional skills required to meet the special health concerns of young people in adult facilities. Services provided to older people with chronic disease such as diabetes are often not suitable for young people transitioning from paediatric services and they may not attend. This can lead to an increased clinical risk that might otherwise have been avoided if suitable services were provided^{5,6}. There are also cases where young people continue to be treated in paediatric hospitals due to a lack of appropriate adult services. As a result of the comprehensive services provided by paediatrics centres, many young people also have limited contact with GPs prior to moving to adult services.

2. Project Context

The Transition Care Workforce Project is set within national and state policy contexts. It links into strategic directions related to the NSW Health workforce and to the provision of chronic care services. The NSW Health document *Future Directions for Health in NSW – Towards 2025*, states that an increasing proportion of those with chronic conditions are younger people and there are few defined transition policies for younger people in NSW⁷. The needs of younger people are now receiving a greater focus as a result of the GMCT Transition Care Network.

A shortfall in the supply of most of the clinical workforce and increased concentration in larger population centres have been identified in state and federal documents⁸⁻¹³. Workforce planning issues have been outlined in reports by the Australian Health Workforce Advisory Committee (AHWAC) and in the NSW Health Workforce Plan. These reports highlight the need for a sustainable and suitably trained health workforce and how this may be achieved. Workforce development and training are discussed in more detail later in the report.

3. Objectives of the Workforce Project

The Transition Care Workforce Project is part of a larger project overseen by the GMCT Transition Care Executive which aims to improve health services to young people in NSW. The primary objectives of the Workforce Project are to identify:

- The specific medical workforce required to manage young people with chronic diseases/disabilities in the adult health system, particularly those with spina bifida, diabetes, other endocrine disorders, gastroenterological conditions and neurological disorders such as cerebral palsy.
- Nursing and allied health needs and the personnel required in the adult health system to enable satisfactory multidisciplinary care of complex illness/disability.
- The core curricula needed to provide education on chronic illnesses and disabilities in young persons to health professionals in university medical training, intern and resident programs, specialist advanced training, College programs, general practice, nursing and allied health education, and in Continuing Medical Education (CME) for postgraduate clinicians and other health professionals.

The initial focus of the project was to:

- Identify the numbers of young people currently attending paediatric and adult services and those transitioning to adult care
- Collect data on the clinical workforce in outpatient and community-based clinics
- Identify service gaps, particularly in adult health facilities

Liaison and consultation with stakeholders and other relevant agencies in workforce management and planning, acute and chronic care facilities and education and training occurred throughout the project.

4. Priority Chronic Health Conditions for Young People

Preliminary work undertaken prior to the commencement of the Workforce Project identified five priority conditions comprising either: a) the most prevalent clinical groups for young people requiring transition from paediatric to adult health care; or b) those with special needs⁴. The conditions are listed below:

Table 1: Priority health conditions for young people

Overall condition	Specific conditions
Diabetes	focus on Type 1
Other endocrine	e.g. thyroid and adrenal gland dysfunction, Turner's syndrome, Addison's disease
Gastroenterology	E.g. Crohn's disease, ulcerative colitis, short bowel syndrome, coeliac disease and other inflammatory bowel conditions.
Neurological conditions	Especially cerebral palsy - moderate to severe
Spina bifida	includes other neural tube defects

The incidence of diabetes, both Type 1 and Type 2, is increasing in younger people and as a result more are requiring adult health services. The increased life expectancy of young people with spina bifida and cerebral palsy has resulted in increased demand for adult services which are either limited or not available. There are large numbers of young people with endocrine and gastroenterological conditions, but relatively limited appropriate adult services. Transition services are either not currently available for these conditions or restricted to a small number of facilities.

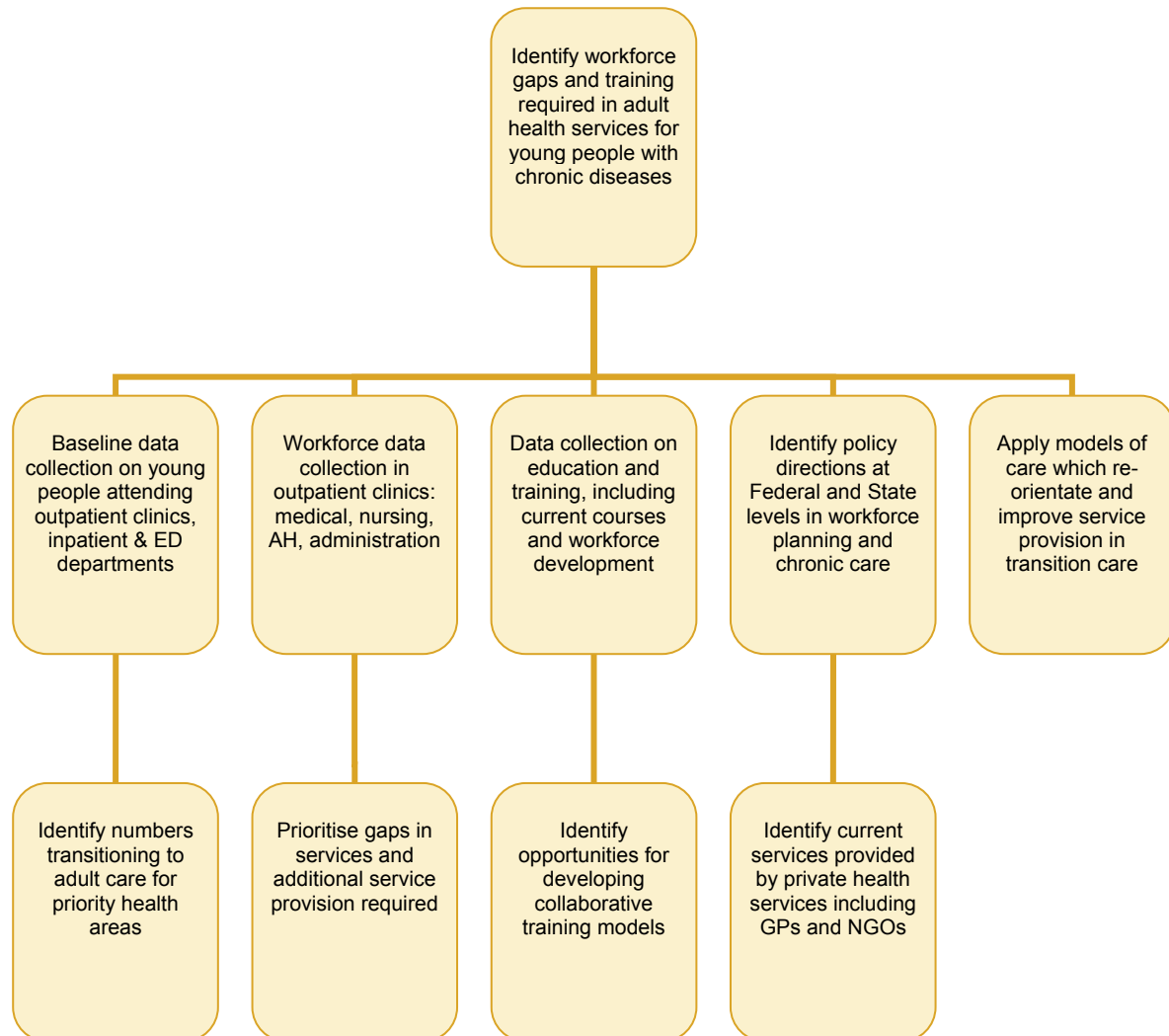
Rare genetic conditions such as connective tissue dysplasias, metabolic, neurogenetic disorders and epidermolysis bullosa have also been included in the workforce project because of a lack of adult clinical services and the high care needs of young people with these conditions.

Other chronic conditions such as asthma and epilepsy have not been included because adult services, although still inadequate in some locations, were identified as being more orientated to the needs of young people compared with those available for the identified priority conditions. Services for cystic fibrosis are being separately explored by the GMCT Respiratory Network and so were not identified as high priority for this project.

5. Project Overview

Figure 1 below shows the major activities undertaken during the project.

Figure 1: Transition Care Workforce – main project components



6. Data Collection

There were three stages to the data collection:

1. Outpatient clinics – patient and workforce data
2. Inpatient and Emergency Department (ED) data
3. Workforce planning and training for transition care

6.1 Outpatient Clinics

Questionnaires were sent to all known outpatient and outreach clinics managing young people with the identified priority conditions in NSW. As a formal list of clinics was not available, the three Transition Care Co-ordinators identified and sent the questionnaire to the relevant clinics. Forms were divided into two sections - patient data and workforce data. The data were entered onto Excel spreadsheets located at the GMCT. The forms for paediatric and adult clinics can be found in **Appendix A**.

6.1.1 Collection of Patient Data

At present, there is no state-wide collection of outpatient and outreach clinic data in NSW that captures detailed information on young people with chronic illnesses. A system is under development¹⁴ but in order to collect baseline data for this project, information had to be obtained on a clinic by clinic basis.

Baseline data were collected on the numbers of young people aged 12 to 24 years with identified chronic conditions attending paediatric and adult services in 2007. The age group 12-24 years is consistent with that used by the Australian Institute of Health and Welfare¹⁵. While some variation exists across the three tertiary paediatric hospitals, most cater for patients from birth to 18 years. The 16-18 year age group is generally comprised of young people with chronic conditions who have been managed long term by the paediatric tertiary centre.

Adult services generally cover young people from the age of 16 years and transition generally occurs around the ages of 16 to 18 although it is recommended that preparation begin in early adolescence.

Patient data items included:

- Total numbers of patients aged 12-18 attending paediatric services and total numbers aged 16-24 attending adult services
- Patients over the age of 18 attending paediatric services and patients under the age of 16 attending adult services
- The number of young people who had transitioned to adult health services in 2007
- Postcode of residence
- Availability of an outpatient data collection system

Extraction of items from the patient administration system (PAS) was requested where possible.

6.1.2 Outpatient Clinic Workforce Data

Workforce data items included:

- Frequency and allocated hours per clinic
- Full time Equivalent (FTE) data on all professions involved in the clinics– medical, nursing, allied health and administrative
- Presence of a waiting list and if so, how long patients wait
- Whether alternative services (public or private) were available for those waiting
- Availability of public allied health clinics to all patients
- Comments regarding adequacy of staffing

6.2 Inpatient and ED Data

Data from the Inpatient Statistics Collection (ISC) and ED collection were extracted from the NSW Health Information Exchange (HIE) using the HOIST data warehouse system¹⁶. All records for each of the priority conditions for young people aged 16-24 from January to December 2007 were extracted. HOIST data report episodes of care, so multiple ISC admissions or ED presentations by the same individual are recorded separately.

Coding for inpatient admission was based on the World Health Organisation's International Classification of Diseases, Revision 10, Australian Modified (ICD – 10 AM). Codes for the first eight diagnoses were used, as chronic conditions are often not the primary cause of admission. ICD-10AM codes for each condition are shown in **Appendix B***.

Coding for ED presentation was based on the first two diagnoses on ICD-9 or ICD-10 AM**. This meant that conditions such as cerebral palsy were unlikely to be extracted, as the young person usually presents for a specific problem arising from the condition rather than the condition itself, which is often not documented. Data are presented by AHS and facility in the results section of this report.

6.3 Comparison and Quality of Patient Data Sources

Data from outpatient clinics were based on the number of individuals attending the clinics in 2007. Data from the ISC and ED collections were collected on episodes of care. While both provide useful information for this study, they cannot be directly compared.

The quality of outpatient data is variable, as information was collected and extracted using different methods. Where data were available in both the hospital patient administration systems and clinics, variations sometimes occurred and some clinics were unable to provide any data. Data on diagnosis and age were not always available so estimates were used. While all efforts were made to verify the patient data by comparing with other sources, it is acknowledged that there are some gaps in this collection.

The ED and ISC data are of higher quality as they are extracted from the HIE and used in the planning and routine monitoring of health programs by NSW Health.

6.4 Workforce and Training Consultations and Documentation

Consultation with key informants and a review of relevant documentation were the primary methods used for the collection of information on workforce planning and training. These included consultations with stakeholders in the health workforce and training sectors related to transition care and included:

- Federal and state government and AHS planning units
- The NSW Institute of Medical Education and Training (IMET)
- The NSW Clinical Excellence Commission (CEC)
- Chronic Care policy officers and service providers at NSW Health and in Area Health Services

* Disease codes in hospital data are only as good as the clarity and completeness of the medical records from which they were coded, the tools available for helping clinical coders and the skill and experience of the coder.

**Many of the data sets in HOIST still use the ninth revision (ICD-9) because of the time lag between the introduction of a new revision and the release of data collections that use the new standard.

Area Clinical Redesign and other innovative projects related to improving chronic care services

- General Practice – including Australian Better Health Initiative (ABHI)
- Non-government organisations involved in the care of young people with chronic conditions such as Northcott Disability Services and the Spastic Centre of NSW
- Clinicians employed by the three NSW Child Health Networks
- Rural clinicians in Dubbo, Bathurst, Orange, Broken Hill and Armidale

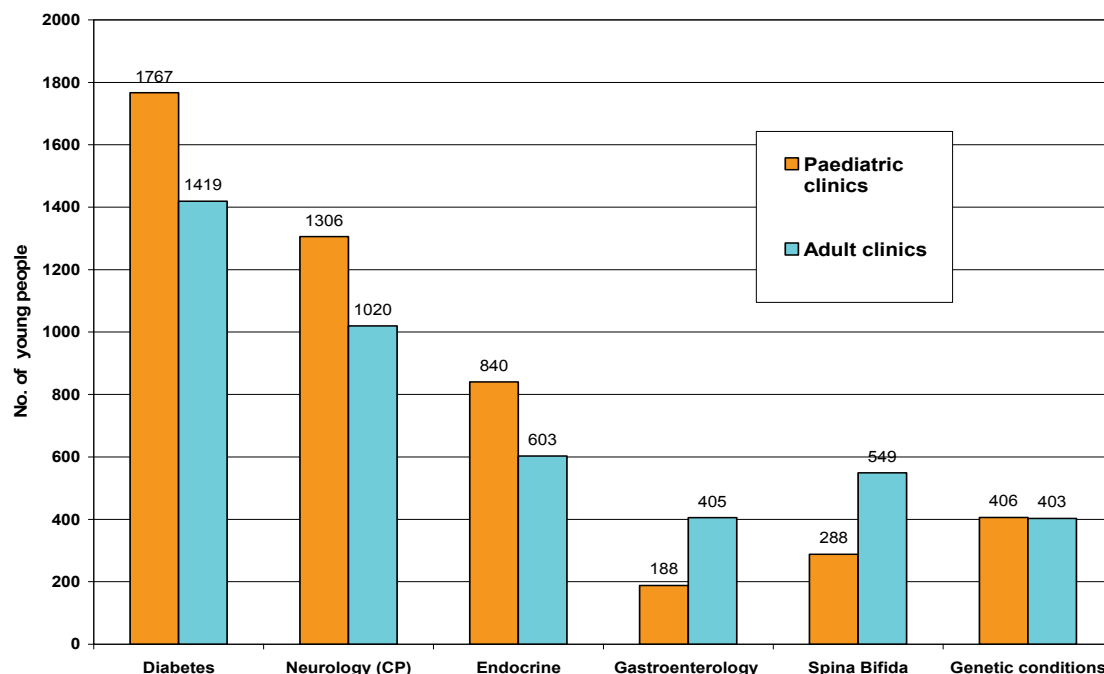
7. Results of Patient Data Collection

7.1 Overview

Information was collected from 156 outpatient and outreach clinics across NSW - 64 paediatric and 92 adult clinics. A total of 8,768 patients with the priority conditions attended these clinics in 2007, as shown in Figure 2. There were 4,823 patients aged 12-18 attending paediatric clinics and 3,945 aged 16-24 attending adult clinics. In the same year, 876 young people transitioned to adult clinics.

NB * There is overlap in the age group 16-18 yrs as young people aged < 18 years attend adult clinics and a significant number > 16 years are seen in paediatric clinics. Wherever possible this overlap was adjusted for.

Figure 2: Numbers of young people attending outpatient clinics in NSW in 2007 for the priority conditions



These results show that for diabetes, endocrine and neurological conditions (mainly cerebral palsy), significant numbers of young people are now attending adult clinics.

Spina bifida shows an expected pattern with increasing numbers of young people surviving into adulthood and moving to adult services. There is now an urgent need for appropriately resourced adult services for these young people.

The pattern for gastroenterology reflects the onset of these conditions in mid teens and increased survival into adulthood although there was some missing data for paediatric clinics.

For rare genetic conditions, the smaller numbers attending adult services reflects the lack of services available for this condition which has resulted in many over the age of 18 years remaining in paediatric services. Data for specific conditions are outlined in Sections 7.2 to 7.7.

The distribution of patients by facility has been mapped separately for metropolitan and outer metropolitan services. The following map shows paediatric services in the Sydney region attended by young people aged 12-18 years with the associated Table 2. This is followed by a map showing adult services attended by young people aged 16-24 years in outer metropolitan and rural areas with the associated Table 3. Two others maps and data for paediatric patients in regional and rural areas and those attending adult services in metropolitan Sydney can be found in **Appendix C**.

Young people 12-18 years attending paediatric outpatient clinics in
Sydney region: 2007

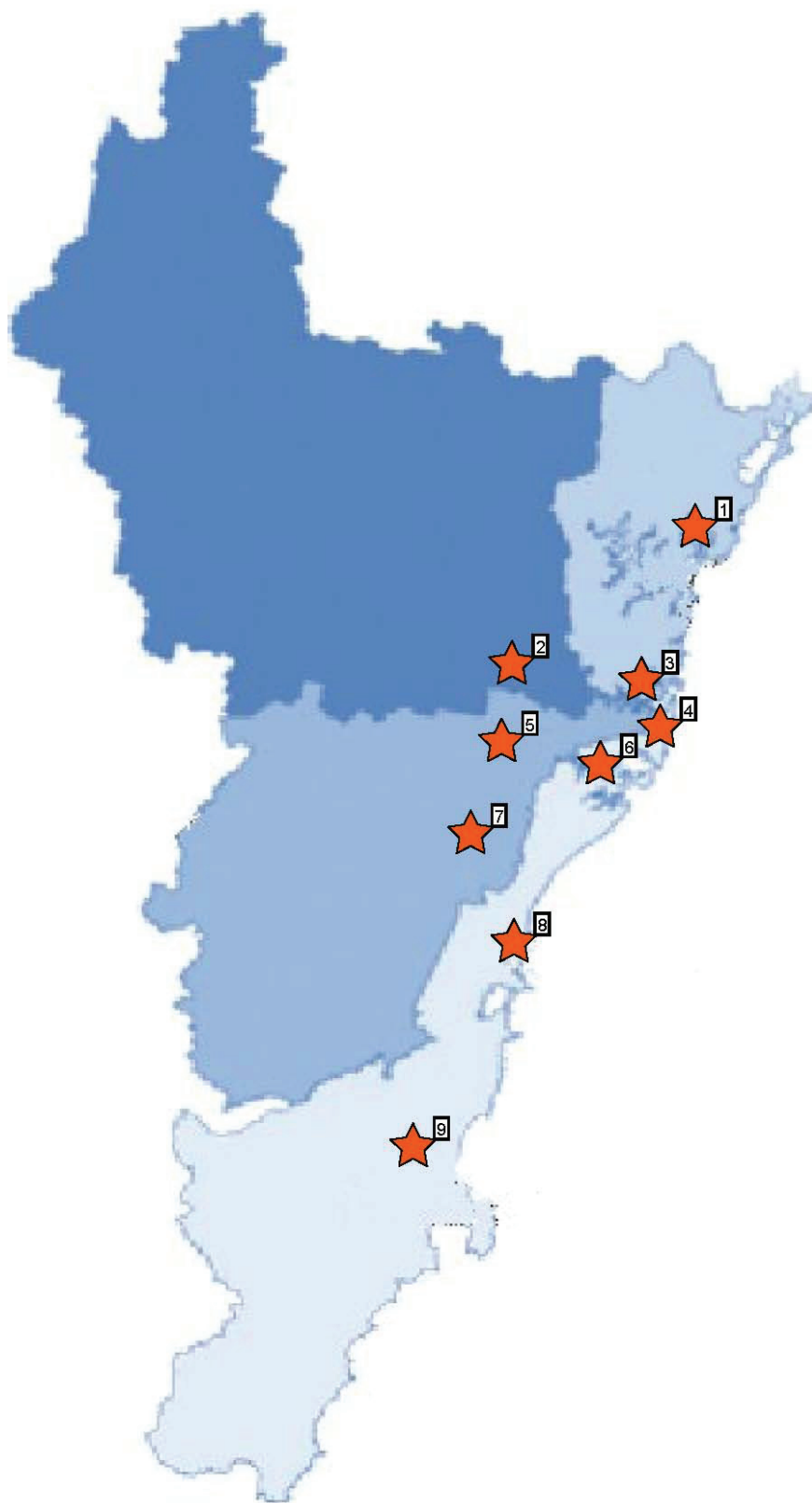


Table 2: Number of patients aged 12-18 years by type of condition and facility in the Sydney metropolitan region

Map reference	Facility	Condition	12-18 years
1	Gosford	Diabetes	45
2	Children's Hospital Westmead	Diabetes	612
		Endocrine	529
		Spina bifida	195
		Cerebral palsy (CP)	444
		Brain injury	204
		Gastroenterology	61
		Metabolic genetics	92
		Limb deficiency	77
		Genetic Connective Tissue Dysplasias	163
		Neurogenetics	391
3	RNS	Diabetes	200
		Endocrine	100
4	SCH	Diabetes	265
		Spina bifida	69
		CP	112
		Gastroenterology	60 (15-18 yrs)
		Epidermolysis Bullosa	4
5	Liverpool	General paed's	40
6	St George Hospital	Diabetes	37
7	Campbelltown	Diabetes	30
		Endocrine	20
		Neurology	24
		Gastroenterology	15
		Spina bifida/CP	10
8	Wollongong	Diabetes	60
9	Shellharbour	Diabetes	25

A map and data for paediatric clinics in regional and rural areas can be found in **Appendix C**

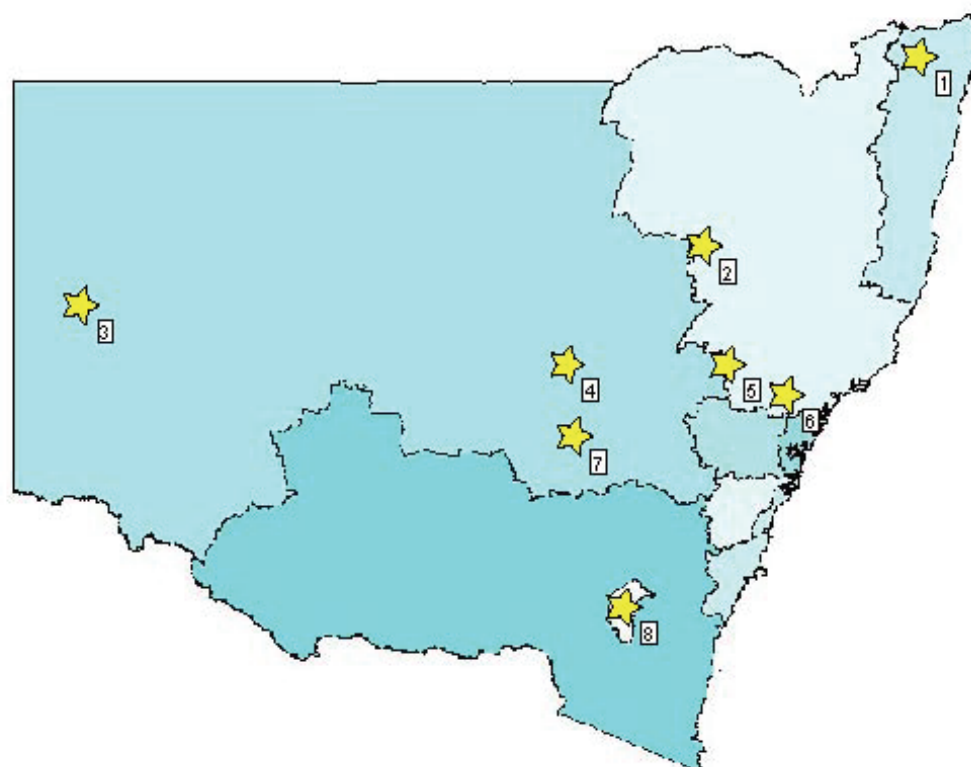


Table 3: Number of patients aged 16-24 years by type of condition and facility in regional and rural NSW

Map reference no.	Facility	Condition	16-24years
1	Tweed Hospital	Diabetes	10
2	Tamworth	Diabetes	20
3	Broken Hill	Endocrine	16
		Gastroenterology	20
4	Dubbo Base	Diabetes	15
5	Maitland	Neurology (CP)	8
6	Newcastle	Diabetes (Transition)	101
		Endocrine	142
		Gastroenterology	53
		Neurology (CP)	347
7	Orange Base	Diabetes (Transition)	20
8	Queanbeyan	Diabetes	30

A map and data for adult clinics in the Sydney metropolitan region can be found in **Appendix C**.

7.2 Diabetes

Table 4 shows the number of young people attending diabetes clinics by age group and AHS. There is some overlap in the age groups attending paediatric and adult clinics. In 2007, 1,767 patients aged 12-18 attended paediatric diabetes outpatient clinics, while 242 transitioned to adult care and 1,419 patients aged 16-24 attended adult clinics.

Table 4: Numbers of young people attending diabetes clinics by age group/AHS

AHS	Paed (12-18 years)	Adult (16-24 years)
CHW	612	208
SWAHS	31	352
SESAHS	387	224
SSWAHS	32	100
NSCCAHS	109	230
HNEAHS	255	227
GWAHS	156	38
GSAHS	124	30
NCAHS	61	10
NSW	1767	1419

There were 1,238 inpatient admissions in NSW for young people aged 16-24 for diabetes in 2007. Average length of stay (ALOS) was three days. There were 448 presentations to EDs in the same year. Admissions and presentations by AHS are shown below (Table 5). Repeat admissions and presentation for the same individual are recorded as separate episodes of care in HOIST. They do not show the number of individuals in an AHS.

Table 5: ED presentations and inpatient admissions for patients aged 16-24 years with diabetes by AHS in 2007

AHS	ED PRESENTATIONS	INPATIENT ADMISSIONS	ALOS (admissions)
CHW	19	46	7
SSWAHS	58	138	3
SESAHS	68	176	4
SWAHS	41	176	3
NSCCAHS	52	171	3
HNEAHS	92	198	3
NCAHS	80	140	2
GSAHS	29	123	2
GWAHS	9	70	2
NSW	448	1238	3

Source: NSW HIE

7.3 Other Endocrine

In 2007, 840 patients aged 12-18 and 89 patients over the age of 18 years attended paediatric outpatient clinics and 62 transitioned to adult care. Six hundred and three patients aged 16-24 and four patients under the age of 16 years attended adult clinics in 2007.

Table 6: Numbers of young people attending endocrine clinics by age group and AHS

AHS	Paed (12-18 years)	Adult (16-24 years)
CHW	529	84
SWAHS	not available	165
SESAHS	not available	60
SSWAHS	20	31
NSCCAHS	104	100
HNEAHS	187	147
GWAHS	4	16
NSW	840	603

There were 118 inpatient admissions in NSW for young people aged 16-24 with other endocrine conditions in 2007, with an ALOS of five days. There were 20 presentations to EDs in the same year.

Table 7: ED presentations and inpatient admissions for patients aged 16-24 years with other endocrine disorders by AHS in 2007

AHS	ED presentations	Inpatient admissions	ALOS (admissions)
CHW	1	19	5
SSWAHS	5	15	6
SESAHS	2	18	5
SWAHS	1	18	8
NSCCAHS	2	9	3
HNEAHS	2	22	4
NCAHS	5	7	1
GSAHS	1	3	2
GWAHS	1	7	2
NSW	20	118	5

Source: NSW HIE

7.4 Gastroenterology

One hundred and eighty eight patients aged 12-18 and five patients over 18 attended paediatric outpatient clinics in 2007. Thirty five transitioned to adult care. Four hundred and five patients aged 16-24 and 15 patients under 16 attended adult clinics in 2007.

Table 8: Numbers of young people attending paediatric and adult gastroenterology clinics by age group and AHS

AHS	Paed (12-18 years)	Adult (16-24 years)
CHW	61	2
SWAHS	n/av	66
SESAHS	60	43
SSWAHS	23	155
NSCCAHS	n/av	66
HNEAHS	37	53
GWAHS	7	20
NSW	188	405

There were 993 inpatient admissions in NSW for young people aged 16-24 with gastroenterology conditions in 2007, with an ALOS of five days. There were 787 presentations to EDs in the same year. Variation in the number of presentations between Area Health Services is likely to be a result of multiple visits by the same person rather than large differences in the number of individuals.

Table 9: ED presentations and inpatient admissions for patients aged 16-24 years for gastroenterology conditions by AHS in 2007

AHS	ED presentations	Inpatient admissions	ALOS (admissions)
CHW	10	93	7
SSWAHS	240	123	7
SESAHS	161	152	3
SWAHS	61	256	6
NSCCAHS	124	128	3
HNEAHS	28	109	3
NCAHS	81	55	2
GSAHS	46	42	3
GWAHS	36	35	3
NSW	787	993	5

Source: NSW HIE

7.5 Neurology (mainly Cerebral Palsy)

Collecting meaningful data on the number of young people with neurological conditions attending ambulatory paediatric and adult services was extremely difficult, largely because of the variation in diagnoses of those who attended the clinics and variety of clinics attended. For example, at John Hunter Children's Hospital young people with a range of neurological conditions including epilepsy, cerebral palsy dystrophies and late effects of cancer treatment attend the neurology clinic. Young people with cerebral palsy (CP) at the Children's Hospital at Westmead may see as many as 10 specialists and it was impossible to cross check that patients were not being included in the data collection several times. The same applies to Sydney Children's Hospital. The neurological data collected at Albury was mainly for young people with acquired brain injury.

Young adults might attend adult neurology clinics, disability clinics or rehabilitation services. Appropriate adult services are scarce, particularly for young people with spasticity and movement disorders. A report published in January 2008 following up young people transitioning from paediatric to adult health services¹⁷ found that approximately 35 young people with CP leave CHW annually. The majority are referred to the physical disability clinic at Westmead. Less complex cases may be referred to the rehabilitation clinics at St Joseph's Hospital at Auburn. They are not followed up by the paediatric team after discharge and little is known about what happens to them. Interviews with the young people after discharge from paediatric services identified many areas where improvements could be made.

Data collected in 2007 from the three tertiary paediatric hospitals found that 1,750 children with CP aged 0-18 years were seen, out of a total of 3,383 who would potentially benefit from treatment¹⁸. Many young people receiving regular treatments such as botulism toxin or intrathecal baclofen struggle to find services in the adult world, and all services are metropolitan-based and have AHS restrictions on funding treatments. Young people leaving CHW with intrathecal baclofen pumps are usually referred to adult pain services experienced in re-filling pumps, but finding someone to oversee their neurological condition is a significant problem.

In 2007, 1,306 patients aged 12-18 with a range of neurological conditions and 84 patients over 18 attended paediatric outpatient clinics, while 267 transitioned to adult care. Adults clinics were attended by 1,020 patients aged 16-24 and by 15 patients under 16 years in 2007.

Table 10: Numbers of young people attending neurology clinics by age group and AHS

AHS	Paed (12-18 years)	Adult (16-24 years)	Comment
CHW	* 648	55	* includes 444 with CP; 204 acquired brain injury
SWAHS	n/av	110	
SESAHS	* 112	425	* mainly CP - 490 on intake list
SSWAHS	* 44	41	* mainly CP
NSCCAHS	Not available	17	
HNEAHS	425	372	* includes all neurological conditions, not just CP
GWAHS	*7	n/av	* CP
GSAHS	*70	n/av	* mainly acquired brain injury
NSW	1306	1020	

There were 535 inpatient admissions in NSW for young people aged 16-24 with CP in 2007. The ALOS was five days. There were eight presentations to EDs in the same year. The low level of ED presentation can be accounted for by patients' attendance for specific problems resulting from the condition, rather than from CP itself.

Table 11: Inpatient admissions for patients aged 16-24 years with cerebral palsy by AHS in 2007

AHS	Inpatient admissions	ALOS (admissions)
CHW	46	6
SSWAHS	67	7
SESAHS	47	4
SWAHS	56	3
NSCCAHS	41	3
HNEAHS	39	3
NCAHS	38	2
GSAHS	17	3
GWAHS	7	4
NSW	535	5

Source: NSW HIE

7.6 Spina Bifida and Other Congenital Spinal Problems

In 2007, 288 patients aged 12-18 were registered with the paediatric spina bifida clinics who responded to the survey. Approximately 238 patients aged 12-18 and 31 patients over 18 attended paediatric clinics in the same year. Seventeen young people transitioned to adult care. Five hundred and forty nine patients aged 16-24 years were registered with adult clinics, although only approximately 40% attended appointments. No patients aged less than 16 attended adult clinics in 2007.

Many young people with spina bifida are lost to follow up and there are inadequate resources to manage the numbers of those aged over 18 in adult health facilities. Table 12 shows the total for each age group.

Table 12: Numbers of young people with spina bifida on clinic registers by age group and AHS **

AHS	12-18 years	16-24 years
CHW	195 registered but 50 lost to contact	12
SWAHS	n/a	65
SESAHS	69 (551 total across all age groups on clinic register)	70
SSWAHS	n/a	Max 70 seen per year but 400 on register
HNEAHS	24	2
NSW	288	549 (approx 210 seen in clinic)

** Numbers do not include approx. 31 young people aged 12-24 identified in the 2006 Illawarra Spina Bifida Project Report as living in the Illawarra region. Many of these young people are registered on the SCH data base and individual patient details could not be obtained to avoid replication of data.

There were 740 inpatient admissions in NSW for young people aged 16-24 with spina bifida in 2007, with ALOS of five days. The reason for the large number of admissions at CHW and SESAHS is likely to be multiple admissions for the same individual e.g. for renal dialysis. Common causes for admission include chronic renal failure, pressure areas/sepsis, chronic respiratory failure and acute shunt dysfunction.

Table 13: Inpatient admissions for patients aged 16-24 years with spina bifida by AHS in 2007

AHS	Inpatient admissions	ALOS (admissions)
CHW	222	3
SSWAHS	61	9
SESAHS	121	10
SWAHS	49	9
NSCCAHS	98	4
HNEAHS	92	8
NCAHS	41	6
GSAHS	31	2
GWAHS	25	4
NSW	740	5

Source: NSW HIE

7.7 Rare Genetic Conditions such as Connective Tissue Dysplasias, Epidermolysis Bullosa and Neurogenetic Disorders

The majority of paediatric patients with rare, complex genetic disorders are currently managed by the Department of Clinical Genetics at the CHW and through its 'sister service', the Western Sydney Genetics Program. Referrals to both services come from all over NSW. They include a range of disorders such as Connective Tissue Dysplasias e.g. Osteogenesis Imperfecta, Arthrogryposis, Marfan syndrome, Skeletal Dysplasias, Ehlers-Danlos syndromes and Mucopolysaccharidoses. Other rare genetic disorders such as Fragile X Syndrome, other rare mental retardation syndromes and Limb Deficiency, require input from a poorly resourced genetic medicine service at Westmead Hospital. There are currently 163 patients aged 12-18 managed by the Connective Tissue Dysplasia Clinic at CHW and approximately 60 aged over 18 years.

The volume of service delivery has been rising every year. The exact number in transition groups is not known because of lack of a Service Coordinator to collate this data. Furthermore the service commenced transitioning its patients over 5 years ago to an Adult Connective Tissue Management clinic at Westmead Hospital offered by Professor Sillence and this transitioned cohort falls into the same category as PKU adults who have been retained at CHW until now.

Young people with neurogenetic disorders such as muscular dystrophy, peripheral neuropathies, myopathies and neurofibromatosis attend dedicated neuromuscular clinics at the three tertiary paediatric hospitals. At CHW, 391 patients aged 12-18 are on the neurogenetic clinic database and 253 aged over 18 are still managed by the paediatric team as there are few appropriate adult services.

The Western Sydney Genetics Program manages patients with rare metabolic conditions such as PKU, Rett syndrome and lysosomal disorders. There are approximately 140 adult patients >18 years with genetic metabolic conditions currently being managed by the Children's Hospital at Westmead and 72 patients managed by the Department of Genetic Medicine at Westmead whose staff are all honorary Clinical Geneticists at Westmead. They face multiple transition issues, as outlined in a recent correspondence from Professor David Sillence, which include the following: ¹⁹

1. Identifying the case load in each disability group and the needs of all the patients requiring transition
2. Preparing transition plans and information and training for health workers
3. Identifying clinicians who can provide/be trained to provide clinical genetic/rehabilitation/AH/endocrinology and orthopaedic surgery and the ancillary management e.g. cardiologists, neurologists
4. Completing the documentation and clinical reviews necessary to achieve transition with smooth graduation to adult services.

Currently there are no resources to help with these issues. All of the disorders encompassed by connective tissue dysplasia are rare and complex. *"Many of these disorders have potential life-threatening complications which sadly at present are known to clinical geneticists but recognised by few other clinicians"* ¹⁹.

Table 14: Patients with genetic metabolic disorders across AHS

AHS	12-18 years	19-24 years	Comments
CHW	92	Approximately 140 patients aged over 18yrs still using CHW outpatient services	PKU is the largest group with approx 40 in total. There are 18 patients aged 14 and 15 There are 47 general metabolic patients aged >13
SWAHS Westmead hospital		145	Approx 145 patients with genetic metabolic disorders excluding Lysosomal Storage Disease (LSD) are managed at Westmead but numbers have been capped since 2005 due to inadequate resources (apart from accepting pregnant women with PKU disorder who require close monitoring). In addition there are 72 adults with LSDs managed by the Department of Genetic Medicine
SESIAHS SCH	5		Minimal numbers of patients in this age group

Table 15: Numbers of young people registered with neurogenetic clinics by age group and AHS

AHS	12-18 years	16-24 years
CHW	391	* 253
SWAHS	0	No data available
SSWAHS	0	13
NSCCAHS	0	7
HNEAHS	15	0
SESAHS	Not available	130
NSW	406	403

* includes 253 people aged over 18 on the CHW database who will transfer to adult services at Westmead once the clinic is established

Epidermolysis Bullosa (EB) is a rare, genetically inherited skin condition in which blisters develop as a result of slight frictions or knocks, or spontaneously. Constant blistering and eroding of the skin surfaces requires daily bandaging. All skin layers are affected including mucosal linings of the body. Young people with EB require complex ongoing multidisciplinary care – the majority see a range of medical disciplines including dermatology, haematology gastroenterology, renal and cardiology and require expert nursing input for their dressings and skin care as well as dieticians and psychologists.

The majority of paediatric patients with EB are managed at Sydney Children's Hospital, with 36 aged 0-18 attending the SCH EB clinic in 2007. Four were aged 12-18 and six were over 18. Young adult patients are currently transitioning to Prince of Wales or St George hospitals but data were not available. Decisions need to be made about appropriate funding of these services.

8. Workforce Outpatient Data

8.1 Overview

Workforce data were collected from 156 outpatient and outreach clinics across NSW comprising 64 paediatric and 92 adult clinics. Due to the qualitative nature of the data, a content analysis was carried out and data are summarised below by condition for each of the priority conditions. Paediatric and adult workforce data are analyzed separately due to differences in clinic structure and workforce.

Gaps in services are based on reported waiting lists and staff comments. A detailed analysis by condition, AHS and facility for both paediatric and adult clinics can be found in Appendices D and E.

8.2 Diabetes

8.2.1 Paediatric clinic workforce data

Data collected from 21 paediatric clinics are summarized below:

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data were collected from electronic PAS systems in four clinics (iPM, Cerner, PEDD, PIMMS), one used an access database, two reported 'yes', one reported 'no' and 13 did not respond to this question.
Frequency of clinic	<ul style="list-style-type: none">• Most clinics (8) were held either two or four times a year, three were held once a month and four once a week or more.
Staffing	<ul style="list-style-type: none">• Most, but not all, were attended by one or more Medical Officer (MO)• Most include nursing staff, a Diabetic Educator and allied health staff, particularly dietitians.
Waiting lists and service gaps	<ul style="list-style-type: none">• Of 10 clinics responding to the question on waiting lists (WL), seven had a WL, two did not, and one didn't know.• Long WLs were reported for John Hunter Children's Hospital, Tamworth, Orange, Dubbo and Wagga hospitals.• Five clinics indicated that staffing was inadequate with shortages in social work, psychologists, dietetics and diabetes education.• Shortages were mainly in regional and outer Sydney areas including Gosford where there was no public endocrinologist available at the time of the data collection.• Lack of access to a dietician at Grafton and lengthy travel to visit an endocrinologist at Coffs Harbour was reported.• A social worker was also required at Coffs Harbour.• At RNS, there have been positive moves with the establishment of a transition clinic.
Referrals to other services	<ul style="list-style-type: none">• Alternative services for those on the WL included a Diabetic Educator or private endocrinologist.• Six clinics referred patients to AH clinics e.g. Diabetic Educator/dietician, and one to a youth health team.
Other information	<ul style="list-style-type: none">• Staff in several clinics commented about loss to follow-up, with young people dropping out of health services in the transition period and not re-appearing until their mid to late 20s.

8.2.2 Adult clinic workforce data

Data was collected from 29 adult clinics including an outreach clinic in Nowra and a diabetes education service in Lithgow. Five clinics for young people were included (Westmead, Nepean, Bankstown, John Hunter Hospital and Orange) and are summarized below:

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data collected was from electronic PAS systems in eight cases (using iPM, Cerner, Chime & Chis). Four used an access database, five had a clinic booking system, eight didn't know and four had no patient data system.
Frequency of clinic	<ul style="list-style-type: none">• Most clinics (10) were held weekly, with six held more frequently.• Clinics were of 3-4 hours duration unless specified.
Staffing	<ul style="list-style-type: none">• Most clinics were attended by one or more Medical Officer.• Nowra, Ryde, Sutherland and Lithgow clinics were staffed by nursing and AH staff.
Waiting lists and service gaps	<ul style="list-style-type: none">• Eleven clinics reported WLs, - generally for patients requiring review, as urgent cases were usually seen straight away. Several clinics did not respond to the question. Further gaps are outlined below.
Referrals to other services	<ul style="list-style-type: none">• Alternative services for those waiting included a Diabetic Educator or private endocrinologist.• Five clinics referred to AH clinics e.g. Diabetic Educator, dietician, podiatry, ophthalmology
Other information	<ul style="list-style-type: none">• Comments included: 'more staff required', 'nurses spending time chasing up young people to attend', 'pump clinic discontinued', 'young people not presenting until over 25 years of age with more serious issues', 'need for a psychologist', 'no transition policy and level of staff inadequate for young adults', 'young people attend only when there is a problem'.

Overall, services for young adults with Type 1 diabetes vary enormously across paediatric and adult facilities and across metropolitan, regional and rural settings. There are few dedicated transition clinics, but those that exist report high attendance and patient satisfaction and there is emerging evidence that such clinics result in improved outcomes for young people transitioning from paediatric services⁶.

Gaps in several adult services for diabetes were reflected by long waiting lists and need for additional staff in some areas e.g. HNEAHS. The John Hunter and Tamworth hospitals report lengthy waiting lists and need for additional staff. There were long waiting lists at Liverpool and at Wollongong, where it was reported that many young people were lost to the system during transition. A lengthy waiting list occurred at Dubbo and also at RNS in Sydney. At RNS, a new monthly transition clinic has recently commenced, co-ordinated by a staff specialist.

Gaps in staffing were reported for the GWAHS, and at Westmead, Liverpool and Royal Prince Alfred (RPA) hospitals. The need for a psychologist was reported at Bathurst, John Hunter Tamworth and POW hospitals. In general, better resourced services provided a young people's service e.g. Westmead, Blacktown and Bankstown.

8.3 Other Endocrine

8.3.1 Paediatric clinic workforce data

Data collected from four paediatric clinics are summarized below.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data was collected from an access database in one clinic and 'practice pro' in another. The two other clinics commented that 'the data was accessible' but there was 'no age breakdown'• No data reported for SCH
Frequency of clinic	<ul style="list-style-type: none">• All clinics are held once a week or more
Staffing	<ul style="list-style-type: none">• All clinics were attended by at least one MO and three by nursing staff• One clinic was staffed by AH staff (physio, dietician and OT)
Waiting lists and service gaps	<ul style="list-style-type: none">• The CHW clinic reported a waiting list of up to 2 months• The endocrine clinics appeared to be providing an adequate service with the exception of RNS, where more nursing staff were needed
Referrals to other services	<ul style="list-style-type: none">• Private endocrinologists were the only alternative service reported for those on a waiting list
Other information	<ul style="list-style-type: none">• The single comment related to need for more nursing staff at RNS

8.3.2 Adult clinic workforce data

Data were collected from 11 clinics including two combined with diabetes.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data was collected from electronic PAS systems in four clinics (using iPM), one had a booking system and six either had no data collection system or didn't know
Frequency of clinic	<ul style="list-style-type: none">• Most clinics (nine) were held once a week or more
Staffing	<ul style="list-style-type: none">• All clinics were attended by at least one MO and seven by nursing staff
Waiting lists and service gaps	<ul style="list-style-type: none">• Most (seven) did not report a waiting list and for those that did, the wait ranged from two weeks to eight months, predominantly for review patients• The endocrine clinics reported waiting lists of two months or more were at RPA, Concord, RNS and Broken Hill hospitals
Referrals to other services	<ul style="list-style-type: none">• Private endocrinologists were the only alternative service reported for those on a waiting list• Three facilities referred to dietician AH clinics
Other information	<ul style="list-style-type: none">• There were no recorded comments for these clinics• The lack of comments about level of staffing suggest that these clinics are adequately resourced

8.4 Gastroenterology

8.4.1 Paediatric clinic workforce data

Data were collected from five paediatric clinics at SCH, CHW, Campbelltown (two clinics) and the JHCH. No workforce data were available from CHW.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data was collected from an electronic PAS system (iPM) in one facility and in one other was reported as 'research based'• Two clinics were included for Campbelltown hospital – the Paediatric Ambulatory clinic and the Obesity clinic• No workforce data reported for CHW
Frequency of clinic	<ul style="list-style-type: none">• Ranged from daily clinics (Campbelltown) to monthly (JHCH) and three per month at SCH
Staffing	<ul style="list-style-type: none">• All were attended by MOs, three by nursing staff and two by dieticians
Waiting lists and service gaps	<ul style="list-style-type: none">• One clinic (JHCH) reported a waiting list of three months• There was a lack of nursing, social work and the support of a psychologist at SCH
Referrals to other services	<ul style="list-style-type: none">• The JHCH reported that because there is no paediatric gastroenterologist there, patients may see the specialist at SCH for their first visit and then follow up in the outreach clinic held at JHCH
Other information	<ul style="list-style-type: none">• The five gastroenterology clinics appeared to be providing an adequate service with the exception of JHCH which relies on outreach medical services from SCH

8.4.2 Adult clinic workforce data

Data were collected from 11 adult clinics including a liver clinic at Nepean and a Crohn's disease clinic at Liverpool.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data was collected from electronic PAS systems in four clinics and three booking systems including a specialist's list. Four clinics did not report a patient list• Data for RNS are likely to be underestimated as only the last appointment is recorded on their PAS (Cerner)
Frequency of clinic	<ul style="list-style-type: none">• Most (10) were held once or more a week
Staffing	<ul style="list-style-type: none">• All were attended by MOs
Waiting lists and service gaps	<ul style="list-style-type: none">• Eight clinics had a waiting list ranging from two weeks to six months with most giving priority to urgent cases• At Liverpool there were no alternative public services and at Westmead only private gastroenterologists were available for those on the waiting list
Referrals to other services	<ul style="list-style-type: none">• Alternative services for those waiting included private gastroenterologists and a Gastric Liaison Nurse in one facility (JHH)• Five clinics referred to AH clinics for dietetics and nutrition
Other information	<ul style="list-style-type: none">• None provided

8.5 Neurology (mainly Cerebral Palsy)

8.5.1 Paediatric clinic workforce data

There were 10 paediatric clinics, comprising four general neurology clinics, one cerebral palsy, one physical disability, one paediatric, one botox and two brain injury clinics. Two clinics at the Children's Hospital Westmead and Tamworth Hospital were included. The clinic at Tamworth had only been held once prior to the data being collected.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data was collected from PAS systems (CIAP, PIMMS or CAPS) in two facilities, an Access or other database in three facilities and the source was not identified in two facilities
Frequency of clinic	<ul style="list-style-type: none">• Clinic frequency ranged from once a week or more (four clinics), monthly (two), to 3-4 times a year (three)• In most general neurology clinics, patients had a range of diagnoses including cerebral palsy but these were not identifiable in the data reported to the GMCT
Staffing	<ul style="list-style-type: none">• All were attended by one or more MOs, five had Clinical Nurse Consultants (CNCs) and 8 had AH staff (mainly physio and OT)
Waiting lists and service gaps	<ul style="list-style-type: none">• Four had a waiting list ranging from 1-6 months, and six did not have a waiting list. Around half of the neurology clinics had a waiting list which was up to six months at the JHCH, with the only alternative being private MOs. There was also a waiting list at Muswellbrook.• Additional staff was required at the botox clinic at Campbelltown, and the brain injury clinic at Albury reported it had 'no extra capacity'. The physical disability/cerebral palsy clinics at CHW and SCH appeared to be providing an adequate service as there were no waiting lists or requests for additional staff
Referrals to other services	<ul style="list-style-type: none">• Three clinics referred patients to AH clinics or other services including a local community health centre, NSW Spastic Centre and NSW Department of Ageing, Disability and Home Care
Other information	<ul style="list-style-type: none">• One clinic (botox) reported that 'more staff was required'. No other comments were recorded

8.5.2 Adult clinic workforce data

Data from 15 clinics were collected including two neuromuscular clinics, one neurogenetics, one rehabilitation, one combined physical disability/cerebral palsy, one brain injury and two cerebral palsy clinics.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Patient data was collected from PAS systems (iPM, Cerner, other) in seven facilities, another system in three facilities and 'not known' in four facilities.• Diagnosis was not available in many instances so the reported data included those with diagnoses other than cerebral palsy.
Frequency of clinic	<ul style="list-style-type: none">• Frequency ranged from six per week to once a month.
Staffing	<ul style="list-style-type: none">• Most (eight) were attended by one or more MOs.
Waiting lists and service gaps	<ul style="list-style-type: none">• Six clinics had a WL ranging from 1-9 months, with three clinics giving priority to urgent cases. In two clinics, the presence or otherwise of a WL was not reported.• Lengthy WLs reported at POW, Liverpool and JHH• Four clinics recorded comments about either the need for more staffing (POW) or funding (Illawarra/Wollongong).• The main staffing shortfalls reported were for clinics at POW including clinic co-ordinators and the need for additional hours for post clinic follow-up by MOs
Referrals to other services	<ul style="list-style-type: none">• Four clinics referred to AH services including OT, social work physiotherapy and neuropsychology
Other information	<ul style="list-style-type: none">• The MO clinics in the Illawarra and Wollongong were discontinued in 2007 and staff from this Area commented there was no funding for transition care

8.6 Spina Bifida

8.6.1 Paediatric clinic workforce data

Data from three clinics at SCH, CHW and JHCH were collected.

Information collected	Comment
IT systems used	<ul style="list-style-type: none">• JHCH clinic extracted patient data from iPM, and CHW collects 'basic patient information'
Frequency of clinic	<ul style="list-style-type: none">• CHW clinic is held weekly, JHCH monthly and SCH fortnightly
Staffing	<ul style="list-style-type: none">• All clinics were attended by MOs, two had an RN (CHW and SCH) and two had AH staff (JHCH and SCH)
Waiting lists and service gaps	<ul style="list-style-type: none">• None of the clinics reported a WL for patient review• There was a WL at JHCH for self-catheterisation and a comment from the service that an RN was required 'to teach self-catheterisation'. JHCH reported service shortfalls across all professional groups.
Referrals to other services	<ul style="list-style-type: none">• Not reported
Other information	<ul style="list-style-type: none">• Staffing for these clinics appeared to be adequate overall, with the exception of JHCH

8.6.2 Adult clinic workforce data

Data from three clinics were collected - RPAH, POW and Westmead.

Information collected	Comment
IT systems used	<ul style="list-style-type: none">• Patient data obtained from a rehabilitation database at Westmead and from clinic lists in the other two facilities
Frequency of clinic	<ul style="list-style-type: none">• All clinics were held once a month and attended by MOs
Staffing	<ul style="list-style-type: none">• All had a WL of between 1-3 months
Waiting lists and service gaps	<ul style="list-style-type: none">• Two clinics (RPAH & POW) reported a lack of resources, both staffing and funding, which resulted in 1-3 months waiting times for appointments at POW• The third clinic (Westmead) reported a lack of access to public clinics in urology, neurosurgery and orthopaedics• POW and RPAH clinics were particularly affected, with staff in both clinics making many comments about a lack of resources. POW did not have any funded dedicated staff for the clinic
Referrals to other services	<ul style="list-style-type: none">• Not reported
Other information	<ul style="list-style-type: none">• All three adult spina bifida clinics suffered from a lack of resources which impacted variably on waiting times

NB: NSW Health has recently allocated funding for a proposal submitted on behalf of the Statewide Spina Bifida Collaborative for a co-ordinated outreach service. It is obvious from the large numbers on databases at adult centres versus the actual numbers who attend each year that large numbers of young people and adults are not being reviewed in specialist spina bifida clinics on a regular basis.

8.7 Rare Genetic Disorders

8.7.1 Paediatric clinic workforce data

Data were reported from three Neurogenetic clinics located at two children's hospitals in NSW. This included the Growth and Neurogenetics clinics at CHW and a Muscle clinic at JHCH. Data was also collected on genetic metabolic conditions from CHW and from clinics managing patients with a range of genetic disorders such as Connective Tissue Dysplasia and limb deficiency.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">• Two paediatric clinics have an access patient database, one uses iPM
Frequency of clinic	<ul style="list-style-type: none">• Two clinics were held monthly. The neurogenetics clinic at CHW is held weekly
Staffing	<ul style="list-style-type: none">• All were attended by one or more MOs, three had a CNC and three had AH staff including physio, genetic counselor, SW and OT
Waiting lists and service gaps	<ul style="list-style-type: none">• The two clinics at CHW had a waiting list, with one prioritizing urgent cases
Referrals to other services	<ul style="list-style-type: none">• The CHW clinics referred to public clinics or AH staff including orthotics, child development, psychologists• CHW Growth Disorders clinic referred to private MOs
Other information	<ul style="list-style-type: none">• An adult pilot Metabolic Genetics clinic at Westmead commenced in May 2008. Young people aged over 18 will transition to this clinic but it will not be able to cater for the large numbers of other young people with complex genetic disorders mentioned previously

8.7.2 Adult clinic workforce data

Data were reported from two facilities, located at Concord (four Metabolic Genetics clinics) POW (one Neuromuscular clinic) and RNS (one Neurogenetics clinic). Workforce data were not available for RNS.

Information collected	Comments
IT systems used	<ul style="list-style-type: none">The four clinics at Concord use Cerner PASRNS (neurogenetics) did not report which type of data collection system was used. POW uses ipM
Frequency of clinic	<ul style="list-style-type: none">Concord has four clinics operating at least once a week, including one held daily. POW holds two clinics per month
Staffing	<ul style="list-style-type: none">Both medical and nursing staff attend the clinics at Concord. No AH staff were reportedPOW has part-time, largely unfunded staff - a neurologist, neuromuscular fellow, geneticist, CNC OT and physio
Waiting lists and service gaps	<ul style="list-style-type: none">No WLs were kept by Concord nor reported by RNS. POW WL averages two months
Referrals to other services	<ul style="list-style-type: none">Not reported
Other information	<ul style="list-style-type: none">An adult Neurogenetics clinic has been proposed for Westmead. POW and Concord both required enhancement funding.The lack of patient and workforce data for these clinics makes it difficult to fully assess these services.

8.9 Epidermolysis Bullosa (EB)

Services for young people include the state-wide paediatric EB service located at Sydney Children's Hospital and adult services at POW and St George hospitals. Workforce data were available from SCH and POW hospitals but not from St George.

Information collected	Comment
IT systems used	<ul style="list-style-type: none">SCH did not report a databaseNo reports from POW and St George
Frequency of clinic	<ul style="list-style-type: none">Clinic at SCH is held monthly
Staffing	<ul style="list-style-type: none">SCH clinic is attended by five MOs (paediatrician, two dermatologists, geneticist, gastroenterologist), two CNCs (pain and EB – both part time), and AH staff including physio, social worker and OTPOW clinic has 0.5 FTE CNC
Waiting lists and service gaps	<ul style="list-style-type: none">No WL at SCHNo report from POW
Referrals to other services	<ul style="list-style-type: none">None reported
Other information	<ul style="list-style-type: none">The POW clinic is under-resourced particularly with allied health staff but did not report any patient attendances due to 'inadequate staffing or facilities'. Support is currently provided by the CNC based at SCH but this is unsustainable.St George has major nursing and allied service gaps and was unable to report any patient data

8.10 Summary of Service and Workforce Gaps

- In paediatric services, the main gaps by condition were for diabetes and neurology. Lengthy waiting lists also existed for the Endocrine clinic at CHW and Gastroenterology clinic at JHCH. A shortfall in staffing for the gastroenterology clinic at SCH was reported. It was not possible to assess the Diabetes and Endocrine clinics at SCH and the Gastroenterology clinic at CHW due to lack of workforce data.
- Adult service gaps across NSW were identified for all priority conditions. The neurology clinics with the largest gaps in services were those located in outer Sydney, Illawarra and the HNEAHS. All three adult spina bifida clinics, particularly the POW clinic, were under-resourced, with lengthy waiting lists and large staff shortfalls.
- The patient and workforce data indicate that adult EB and genetics clinics are markedly under-resourced. Paediatric clinics for rare, complex genetic conditions at CHW have also been under pressure with many patients older than 18 attending the services. Discussions are underway to develop a state-wide adult service for complex genetic conditions and a pilot has begun at Westmead for metabolic patients.
- HNEAHS reported many gaps in services and lengthy waiting lists for children and adults. JHCH appeared to be under-resourced for four of the five priority conditions, with the exception of endocrine. Adult services at the JHH showed significant gaps in services for diabetes, gastroenterology and neurology.
- Hospitals in outer metropolitan areas including Gosford, Liverpool, Campbelltown and the Illawarra reported waiting lists and staffing shortfalls for many services. These include diabetes (child and adult), gastroenterology (adult) and neurology (adult).
- Shortfalls in diabetes services were reported in many rural areas both for adults and children. These include Dubbo, Orange, Grafton and Coffs Harbour. More transition clinics were required for the increasing numbers of young people with Type 1 diabetes. Additional staffing, in particular for public endocrinologists, psychologists, Diabetic Educators and dietitians were required.
- Workforce data for endocrine services were not complete but most appeared to be adequately staffed. However, waiting lists were reported at several adult clinics and one paediatric clinic.
- Wide variation in the types of patient data collection systems used was reported. Many clinics either did not respond to the question or didn't know what system was available. Some reported that there was no data collection system in place.

The two tables below are a summary of level of service gap by condition and type of facility (paediatric or adult). The services have been categorised by the extent of the gap in service by use of three categories: minor gaps/adequate service, moderate gaps, major gaps. The rating system is based on the presence and length of a waiting list (WL) combined with comments about additional staff required. The length of the WL was categorised as:

- minor gaps – no waiting list or up to two weeks and no staff shortages
- moderate gaps – wait of between two weeks and three months and no significant staff shortages
- major gaps – wait of over three months and significant staff shortages

The table can be cross-referenced with the workforce summary for each facility provided in Appendices D and E.

Table 16: Summary of service gaps by condition and type of service required

CONDITION AND GAPS	TYPE OF CARE REQUIRED AND LEVEL OF ADULT HEALTH SERVICE NEEDED
DIABETES	
Major gaps	Paediatric: JHCH, Tamworth, Orange and Dubbo hospitals have long waiting lists and/or staffing shortfalls Adult: Liverpool (very long WL), JH/RN (WL and need a psychologist), Concord, Auburn, Tamworth (need staff and a TC clinic), Dubbo and Orange
Moderate gaps	Paediatric: Coffs Harbour, Wagga, Armidale, Gosford (recent service improvement), Grafton, Ballina/Lismore Adult: Wollongong, St George, Sutherland, POW, RNS
Minor gaps or adequate service	Adult: Ryde, Queanbeyan, Broken Hill Bankstown, Nepean, Blacktown, Westmead (the last four are clinics for young people)
OTHER ENDOCRINE	
Major gaps	Paediatric: CHW Adult: RNS, Broken Hill, Concord
Moderate gaps	Adult: POW
Minor gaps or adequate service	Paediatric: RNS, Campbelltown, JHCH Adult: Campbelltown, Blacktown, Nepean, Westmead (social worker required)
NEUROLOGY	
Major gaps	Paediatric: JHCH Adult: POW neuromuscular and neurology clinics, Illawarra & Wollongong CP services (MO clinic discontinued), Liverpool brain injury clinic, JH/RN
Moderate gaps	Paediatric: Campbelltown botox and neurology clinics, Muswellbrook Adult: Campbelltown, St Joseph's rehab clinic, Gosford, Albury Brain Injury.
Minor gaps or adequate service	Paediatric: none reported Adult: Westmead, Concord Neurology, Maitland
GASTROENTEROLOGY	
Major gaps	Paediatric: none Adult: JHH, Liverpool, Westmead
Moderate gaps	Paediatric: JHCH Adult: RNS, Gosford, RPAH, Broken Hill
Minor gaps or adequate service	Paediatric: SCH, Campbelltown Adult: POW, Nepean
SPINA BIFIDA	
Major gaps	Paediatric: none Adult: POW, RPAH (both lack of dedicated or adequate staffing), Westmead (lack of public services)
Moderate gaps	Paediatric: JHCH (WL for self-catheterisation services) Adult: none
Minor gaps or adequate service	Paediatric: CHW, SCH Adult: none

RARE GENETIC CONDITIONS	
a) Neurogenetics	
Minor gaps	Paediatric: CHW Growth and Neurogenetics clinics, (transition-aged patients recently moved to new adult state-wide clinic at Westmead)
Moderate gaps	Adult: Concord and POW both under-resourced for allied health staff
b) EB	
Major gaps	Adult: POW and St George EB clinics did not provide data but conditions are reported as extremely under-resourced
Moderate gaps	Paediatric: more hours are needed for the CNC at SCH. There is only an outreach clinic at JHCH.
c) Metabolic conditions	
Major gaps	Adult: Enhancements are urgently needed across all professional groups as indicated in the 2008 SWAHS metabolic proposal Paediatric: Need a Professional Service Coordinator across the connective Tissue Dysplasia Service at CHW which is the second largest service offering rehabilitation
d) Other genetic conditions	
	Adult: Enhancements are urgently needed across all professional groups
	Paediatric: Approximately 50% of patients aged over 18 are still being managed in a paediatric facility and several hundred patients now require urgent transition to adult health services. Need a CNC for the Tissue Dysplasia Service at CHW

8.10 Training shortfalls and solutions by condition

Diabetes – Type 1

Shortfalls

- There are adequate numbers of endocrinologists in metropolitan Sydney although distribution varies and some areas such as Liverpool have service gaps. Many adult endocrinologists predominantly see patients with Type 2 diabetes
- Most regional areas experience some degree of service shortfall but these appear to be most pronounced in the Hunter and Illawarra regions

Solutions

- More education for GPs, allied health staff and nurses working in adult services is required for Type 1 diabetes transition care issues
- More Diabetes Educators are required in rural areas e.g. Dubbo, Orange, Coffs Harbour and Grafton

Other endocrine

Solutions

- As for Type 1 diabetes regarding adult clinical staff
- More education required on congenital endocrine conditions across all professional groups

Cerebral palsy, spina bifida and developmental disability

Shortfalls

- There is a lack of knowledge about the needs of young people with these conditions across all professional groups in adult services
- Lack of training opportunities exist for all professions in adult health services including nursing e.g. disability nursing training no longer exists
- Shortage of orthotics in adult services
- Workforce issues are particularly acute for outer metropolitan services

Solutions

- A model has recently been developed by the Statewide Spina Bifida Collaborative and submitted to NSW Health, recommending that a full time Clinical Nurse Consultant and part time allied health professional be employed to develop, establish and co-ordinate a collaborative Statewide Outreach Health Team for adults with spina bifida.

‘There is evidence that dedicated adult clinic services can reduce morbidity and mortality and enrich quality of life if adequately funded to support this group of patients with complex needs’²⁰

A model has also been developed by clinicians working with young people with developmental disability and submitted to NSW Health recommending a medical registrar training position be created at Westmead. Such a position would benefit young people across a broad range of chronic illness groups

Gastroenterology

Shortfalls

- There are adequate numbers of gastroenterologists across most areas of greater metropolitan Sydney but access to specialists and other clinical staff interested in caring for young people is more difficult in outer metropolitan areas e.g. Gosford, Illawarra, Campbelltown and Liverpool

Solutions

- More services orientated to the needs of young people are required especially in outer metropolitan areas

Rare Genetic Conditions

Shortfalls

- The majority of paediatric patients with rare complex genetic conditions including rare metabolic disorders such as PKU, plus connective tissue disorders such as osteogenesis imperfecta, have traditionally been managed by CHW. A much smaller group have been managed at SCH (< 10) and by specialists from CHW running outreach clinics at JHCH. For Connective Tissue Disorders, the service at CHW is the only multidisciplinary referral centre in NSW and receives regular referrals from SCH and JHH paediatric services.
- Approximately 50% of patients aged over 18 are still being managed in a paediatric facility and several hundred patients now require urgent transition to adult health services
- The main workforce shortfalls include adult medical specialists and registrars, dieticians, clinical nurse specialists and administrative support. FTE have been outlined in the 2007 proposal to the SHIP Committee at SWAHS.

Solutions

- Adult services need to be established that can manage all genetic disorders, not just a specific group such as metabolic. An appropriate adult service for these cohorts of young people and adults is currently being developed at Westmead Hospital. Funding issues for recurrent management will require ongoing negotiation with the three tertiary paediatric hospitals.
- NSW enhanced services at both Westmead adult and SCH in the 2008 budget but the enhancement is insufficient to fund the service at Westmead at the level of sustainability.

Epidermolysis Bullosa

- The majority of young patients with EB are currently managed at SCH. There are 36 patients attending clinics at SCH, eight of whom are aged > 18yrs. Adult patients are currently managed at St George and POW hospitals
- Although there are relatively small numbers of patients with EB state-wide, these young people have complex needs particularly around dressings and wound management and consultations are intensive and time consuming
- All require access to gastroenterology, pain services, haematology (for iron infusions) and plastic surgery (for removal of skin cancers). Most are on home enteral nutrition
- Issues that need to be addressed in development of a service model include:
 - Identification and funding of an appropriately resourced adult service that provides equity of access to multidisciplinary outpatient care
 - Funding of suitable dressings and other equipment needs
 - More nursing hours for the current part-time CNC position based at SCH

9. Workforce Planning and Training for Transition Care

9.1 Overview

An objective of this project was to identify the medical, nursing and allied health workforce required to manage young people with chronic diseases and disabilities in the adult health system in NSW. This includes outpatient and inpatient hospital plus community outreach services and General Practice. Training requirements for new and existing health professionals are included.

Consultations were held with NSW Department of Health, Area Health Services, the Institute of Medical Education and Training (IMET), non-government and private sector health services including General Practice. Liaison with the non-government sector was by key informant interview and also by their representation on GMCT Transition Network Executive and working groups.

9.2 Workforce achievements to date

The GMCT Transition Care Network has already initiated, supported and funded transition projects in NSW, particularly in the area of diabetes, spina bifida and mental health. These projects have included a workforce component. A project specific to allied health transition workforce requirements was funded in the HNEAHS in 2006.

All AHSs in NSW have included transition in their most recent Clinical Service Plans and several have formed Transition Working Groups. State and federal initiatives are also in place to improve adult chronic care health services. NSW Health supports initiatives which are multidisciplinary in approach, stratified by risk, reduce ED presentations and inpatient admissions and strengthen private and public partnerships e.g. with GP Networks^{21,22}. Each AHS in NSW is undertaking clinical redesign projects to improve access to services for people with chronic illnesses. The project in NSCCAHS is based on the Wagner model which is a US integrated multidisciplinary model. This model is based on patient self-management, with the GP as the primary care manager in complex care cases²³.

Each AHS in NSW is also developing an Area Clinical Workforce Plan, initially focusing on analyses of supply and demand then aligning workforce projections to clinical service plans²⁴⁻²⁵.

Interstate chronic disease initiatives include the Hospital Admission Risk Program (HARP) for chronic disease management by the Victorian Department for Human Services²⁶. The same department has developed programs of integrated multidisciplinary care for cancer services. Other Australian transition initiatives include the program established at Royal Melbourne Children's Hospital and the Western Australia Transition Network^{27,28}.

In the UK, an 'Expert Patient' program was developed by the Department of Health in 2001 to encourage patient and clinical organisations to focus on self-management in chronic care services²⁹. Canada and the USA are also leaders in the field of transition.

9.3 Workforce recommendations (for recommendations for specific conditions see Section 8.10)

The main solutions for transition care workforce planning arising from the consultations are:

- Continuation of strategies known to be effective such as Transition Co-ordinators across the Child Health Networks and in specific key sites such as the three tertiary paediatric hospitals – review after three years
- All AHSs to establish Transition Committees to identify priorities for transition and develop Area-specific strategies to meet workforce requirements
- Provision where possible of case management for young people with complex chronic illnesses such as spina bifida. There is increasing evidence that having a central person to help co-ordinate care ensures better outcomes for young people in the early period after they leave paediatric services
- Adopting a multidisciplinary approach to managing young people in the adult health system and providing equity of access to appropriate services
- Increasing the proportion of appropriately skilled medical, allied health and nursing staff by re-skilling the existing workforce and training new clinical staff in transition care to meet service gaps
- Increasing the role and training of GP practice nurses, particularly in rural and regional areas of NSW
- Increasing the training and recruitment of professionals in short supply e.g. rare genetic disorders, spina bifida, developmental disability and orthotics
- Addressing staff retention, succession planning and the retraining of expert staff to cover a range of health conditions
- Implementing models of care which include a single point of access and involve GPs in case co-ordination
- Promoting self-management and illness prevention for patients and their carers, using strategies such as telephone health coaching
- Focusing on the patient journey and involvement of the primary carer
- Piloting models – e.g. multidisciplinary redesign Wagner model with GP involvement in complex care
- Integration of public and private services including GPs (see AHBI) and NGOs
- Identifying sources of funding for proposed models of care

9.4 Education and training initiatives and recommendations

There are many innovative clinical training programs in NSW developed by NSW Health, AHSs, IMET, General Practice and other training and health agencies. The GMCT Transition Network is endeavouring to bring key stakeholders together to focus on unmet needs around transition for young people with chronic illnesses.

Recent GMCT transition initiatives to date:

- A forum held in April 2008 was attended by 140 clinicians and consumers, focusing on a broad range of transition issues
- Development of models of care for the majority of chronic illnesses arising in childhoods (Appendix F)
- Specific projects for spina bifida, mental health and cerebral palsy
- Support for a proposal to develop a registrar training position in intellectual disability, to be based at the Department of Rehabilitation at Westmead Hospital
- Development of e-learning packages including webcasts for nursing and allied health staff via telemedicine and rural institutes: eg. brain injury, gastroenterology and renal
- Support to develop collaborative paediatric/adult clinics e.g. new metabolic genetics adult clinic at Westmead Hospital
- Development of links with the ABHI GP networks
- Development of transition packs for key areas in both paediatric and adult hospitals
- Education sessions on transition provided at the three tertiary paediatric hospitals

Recommendations for education and training and for patient clinical systems are outlined separately below.

Recommendations – education and training

- Building on existing models such as providing Transition Co-ordinators across the three Child Health Networks who in turn educate others in transition issues; employing transition co-ordinators in paediatric hospitals
- Increased use of e-learning options especially for rural and regional centres
- Promotion of the 2008 GP Resource Kit (2nd edition) which includes practical advice on transition³⁰.
- Focusing on the development of core competencies for young people with chronic illness/disabilities
- Providing increased skills in case management
- Expanding the role of practice nurses in GP surgeries to include transition planning
- Succession planning for clinicians who are about to retire
- Training ED staff to identify young people repeatedly presenting and increasing ED liaison with GPs to reduce the number of presentations e.g. using clinical protocols and electronic tracking systems for frequent presenters
- Encouraging young people to be more proactive in self-management and documentation of their condition e.g. via the NSW Health 'Red Book.'

Recommendations specific to IT requirements and patient clinical information systems

- All outpatient clinics need to have a user friendly electronic data collection system with consistent state-wide data items eg. age, diagnosis
- Establish Area Patient Administration Systems so they collect consistent state-wide outpatient data items and routine reports can be easily extracted
- Clinical and administrative outpatient clinic staff should receive regular training so they can enter data and extract reports from clinic data systems
- Explore any variations in rates of ED presentation and admission by condition using ISC and ED data (where there are higher than expected age-standardised admission/ presentation rates by condition)

9.5 Closing summary

The project objectives were to identify the medical, nursing and allied health workforce required in adult services to enable satisfactory multidisciplinary care of complex illness for young people with identified priority conditions.

Recommendations were divided into three sections:

- Workforce
- Education and training
- IT requirements and patient clinical information systems

The workforce recommendations included the continuation of existing strategies and introduction of new initiatives such as increasing the role of GP practice nurses in regional and rural areas of NSW and the recruitment and training of professionals in short supply.

Education and training recommendations build on models initiated by the GMCT e.g. the use of e-learning in regional and rural areas. Other initiatives include training ED staff to identify young people with chronic conditions who are repeat presenters and to liaise with their GPs.

Recommendations for improved patient clinical systems support those already under development by the NSW Health CHOCIP program. All outpatient clinics need an electronic data collection system with appropriate staff training so that the data are straightforward to enter and to extract.

In summary, transition issues for young people with chronic illness/disabilities are receiving increased attention across the health sector throughout NSW. Systems and processes to improve the transition experience for young people and their families are under review in both paediatric and adult services and significant progress has been made over recent years. This Workforce Report documents the way forward and highlights specific recommendations that need to be implemented to ensure provision of equitable, accessible health services for these young people now surviving into adulthood in increasing numbers.

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Appendix A



PAEDIATRIC OUTPATIENT DATA FORM

Name of outpatient clinic
Hospital name
Area Health service
Name & position of clinic contact
Telephone number

Table 1.1: Paediatric data on young people aged 12 to 18 years for the 'key' and 'priority' health conditions plus 'outliers' aged more than 18 years

Data item	Information collected
Health condition(s) managed in clinic	
Total numbers of young people aged 12-18 currently managed by the clinic	
Numbers of people over 18 years managed by the clinic - and age if available	
Number of patients who transitioned from July 2006-June 2007	
Are postcodes or suburb (total for each PC or suburb) available?	
Is an outpatient database available? If database available – please describe type of system	
Other comments eg. How accessible is the data?	

Table 1.2: Paediatric Workforce data for the nominated clinic

Data item	Information collected
Frequency of clinic eg. Monthly	
Allocated hours per clinic	
Number and type of medical staff by FTE	
Number and type of nursing staff by FTE	
Number and type of allied health staff by FTE	
Number and type of admin and other non-clinical staff by FTE	
Is there a waiting list? If so, for which disciplines?	
If a waiting list – is an alternative service offered and if so, what is offered?	
Are patients referred to a specialist allied health clinic and if so – please name clinic	



ADULT OUTPATIENT CLINIC DATA FORM

Name of outpatient clinic
 Hospital name
 Area Health service
 Name & position of clinic contact
 Telephone number

Table 2.1: Adult clinic data on Young people aged 16 to 24 years for the 'key' and 'priority' health conditions and those younger than 16 years

Data item	Information
Health condition(s) managed in clinic	
Total numbers of young people aged 17-24 currently managed by the clinic	
Total numbers of young people aged less than 16 years currently managed by the clinic	
Are postcodes or suburb (total for each postcode or suburb) available?	
Is an outpatient database available? If database available – please describe type of system	
Other comments eg. accessibility of the data	

Table 2.2: Adult workforce data for the nominated clinic

Data item	Information collected
Frequency of clinic eg. Monthly	
Allocated hours per clinic	
Number and type of medical staff by FTE	
Number and type of nursing staff by FTE	
Number and type of allied health staff by FTE	
Number and type of admin and other non-clinical staff by FTE	
Is there a waiting list? If so, for which disciplines?	
If a waiting list – is an alternative service offered and if so, what is offered?	
Are patients referred to a specialist allied health clinic and if so – please name clinic	
Other comments eg accessibility of the data	

Appendix B

Diagnosis for 'top 5' conditions – ICD 10AM codes

Condition	Code	Diagnosis
Diabetes – Type 1	E10.1	DM with acidosis with and without coma
	E10.2	DM with renal complication
	E10.3	DM with ophthalmic complication
	E10.4	DM with neurological complication
	E10.5	DM with circulatory complication
	E10.6	DM with other specified complication including hypoglycaemia
	E10.7	DM with multiple complications
	E10.8	DM with unspecified complication
	E10.9	DM without complication

Condition	Code	Diagnosis
Endocrine - other	E89.2	Postprocedural hypoparathyroidism
	E05.9	Thyrotoxicosis
	E03.9	Hypothyroidism
	E23.0	Hypopituitarism
	E05.0	Thyrotoxicosis with diffuse goitre
	E21.3	Hyperparathyroidism, unspecified
	E23.2	Diabetes insipidus
	E 25.0	Congenital adrenogenital disorders associated with enzyme deficiency
	E03.1	Congenital hypothyroidism without goitre
	Q96.9	Turner's syndrome
	E03.9	Hypothyroidism
	E23.0	Hypopituitarism
	Q98.0	Klinefelter's
	Q85.83	Von Hippel Landau
	E27.1	Addison's Disease
	E05	Hyperthyroidism
	M82.1	Osteoporosis

Condition	Code	Diagnosis
Gastroenterology	K51.3	Ulcerative (chronic) colitis rectosigmoiditis
	K50.1	Chrohn's disease of large intestine
	K50.0	Chrohn's disease of small intestine
	Z43.1	Attention to gastrostomy
	T85.5	Mechanical complication of gastrointestinal prosthetic device.
	K51.8	Other ulcerative colitis
	K51.9	Ulcerative colitis, unspecified
	Z93.1	Gastrostomy status
	K50.8	Other Chrohn's disease
	K90.0	Coeliacs disease
	K29.4	Chronic atrophic gastritis
	K50.9	Chrohn's disease, unspecified
	K51.2	Ulcerative (chronic) proctitis

Condition	Code	Diagnosis
Spina Bifida	Q05	Spina Bifida
	Q06	Other congenital malformations of spinal code

Condition	Code	Diagnosis
Cerebral Palsy	G80.8	Other cerebral palsy
	G80.03	Spastic quadriplegic cerebral palsy
	G80.9	Cerebral palsy, unspecified
	G80.4	Ataxic cerebral palsy

Appendix C

Additional maps showing outpatient clinic data

Young people aged 12-18 years attending outpatient clinics in NSW: 2007

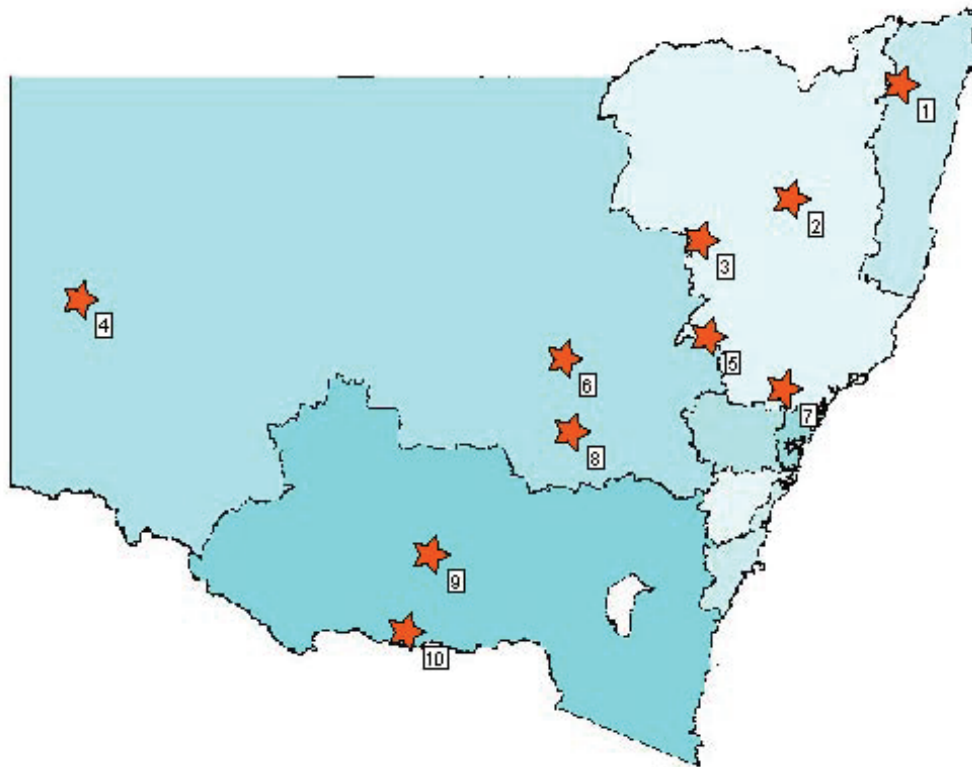
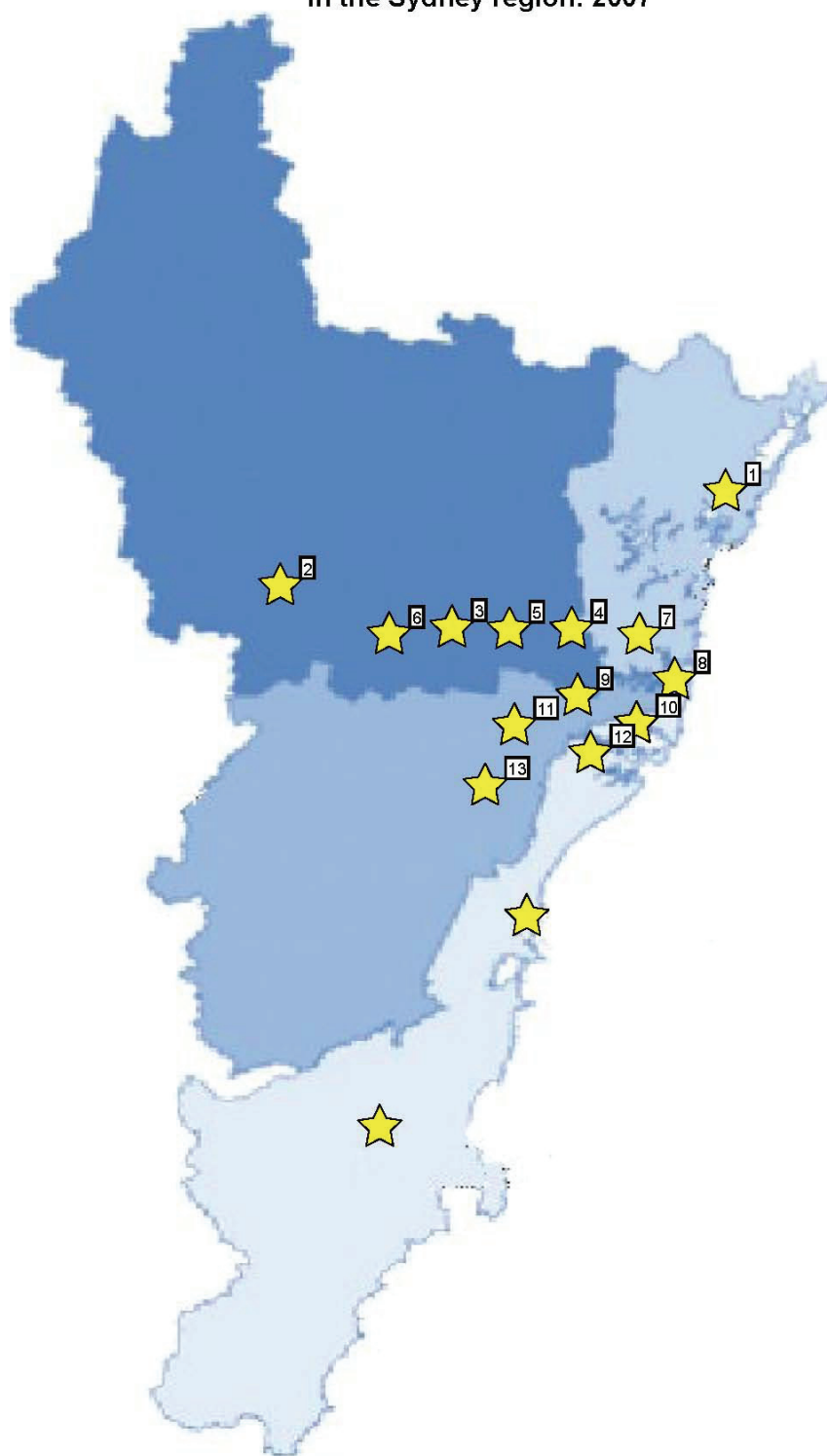


Table showing the number of young people aged 12-18 years attending regional and rural outpatient clinics in NSW in 2007 by map reference number

Map reference no.	Facility	Condition	Nos. aged 12-18years
1	Ballina / Lismore	Diabetes	16
1	Grafton	Diabetes	17
1	Coffs Harbour	Diabetes	28
2	Armidale	Diabetes	16
3	Tamworth	Diabetes	20
		General paed's	6
4	Broken Hill	Diabetes	10
5	Muswellbrook	Neurology (CP)	6
6	Dubbo	Diabetes	46
7	John Hunter Children's	Diabetes	206
		Endocrine	187
		Spina Bifida	24
		Gastroenterology	37
		Neurology (CP)	413
8	Bathurst	Diabetes	50
	Orange	Diabetes	50
9	Wagga Wagga	Diabetes	72
10	Albury	Diabetes	52

Young people 16-24 years attending adult outpatient clinics
in the Sydney region: 2007



The table overleaf shows the number of young people aged 18-24 years attending outpatient clinics in NSW in 2007 by map reference number.

Note: References 14 and 15 refer to services in Wollongong and Shoalhaven (Illawarra) which are not numbered on this map.

Map reference no.	Facility	Condition	Nos. aged 16-24years
1	Gosford	Gastroenterology	59
		Neurology	10
2	Lithgow	Diabetes	15
3	Blacktown	Diabetes	31
		Endocrine	21
4	Auburn Diabetes Education Service	Diabetes	7
	Ryde	Diabetes	30
	St Joseph's, Auburn	Rehab	15
5	Westmead	Diabetes (transition)	254
		Endocrine	136
		Cerebral Palsy	95
		Gastroenterology	50
		Spina Bifida	65
6	Nepean	Diabetes	45
		Endocrine	8
		Gastroenterology	16
7	Royal North Shore	Diabetes	200
		Endocrine	100
		Gastroenterology	7
		Neurology	7
		Metabolic genetics	7
8	Prince of Wales	Diabetes	34
		Endocrine	60
		Neurology	216
		Neuromuscular	130
		Gastroenterology	40
		Spina Bifida	50
	St Vincent's	Diabetes	6
9	Concord	Diabetes	6
		Gastroenterology	55
		Neuromuscular	20
		Metabolic genetics	13
10	Royal Prince Alfred	Diabetes	50
		Endocrine	27
		Gastroenterology	30
		Spina Bifida	400 but 270 active
11	Liverpool	Diabetes	18
		Gastroenterology	70
12	Bankstown	Diabetes (transition)	20
12	St George	Diabetes	76
12	Sutherland	Diabetes	20
13	Campbelltown	Neurology	21
		Endocrine	1
14	Wollongong	Diabetes	70
		Cerebral Palsy	50
	Illawarra service	Cerebral Palsy	27
15	Shoalhaven	Diabetes	25

Appendix D

Paediatric workforce data summary for NSW outpatient clinics in 2007

Data from a total of 64 paediatric clinics is summarized below by condition and Health Area. The summary includes the 'top 5 conditions' of diabetes, other endocrine, spina bifida, cerebral palsy and gastroenterology. Haemophilia and metabolic genetics are also listed as there are gaps in outpatient services for young people with these conditions. In addition, a small number of other clinics e.g. general outpatients clinics which service young people are listed and the details are in the Excel database.

All data collected from service providers has been entered into an Excel database located at the GMCT. Gaps in services are highlighted in the following sections, based on reported waiting lists and staff comments. The adult workforce summary is reported separately.

Diabetes Area Summary – 21 clinics

Children's Hospital Westmead:

- Weekly clinic staffed by 3-4 endocrinologists and a registrar and Fellow. OPD nurses help when available and 1-2 diabetic educators and a dietician attend. There is a waiting list. Private rooms are the alternative for those waiting and individual appointments are made with the dietician and educator if more time is needed.

SESAHS:

- Sydney Children's hospital (SCH): no workforce data for diabetes
- St George: a paediatric clinic is held every 2 weeks staffed by an endocrinologist, RN and AH staff (dietician, podiatry, psychology). There is a waiting list but an educator is available for urgent cases.
- Shoalhaven: 2 outreach clinics per year.
- Wollongong: 4-6 clinics are held per year staffed by 2 endocrinologists from SCH, a dietician and diabetes educator,

SSWAHS:

- Campbelltown: weekly clinic staffed by visiting endocrinologists and an RN. No waiting list

NSCCAHS:

- Royal North Shore (RNS): 3 diabetes clinics per week; service staffed by two endocrinologists, two educators (1 CNC, 1 CNS), 2 part time dieticians, 1 psychologist 2 days per week – no diabetes manager. ***'A monthly transition clinic run by an endocrinologist has recently commenced'***
- Gosford: weekly outreach clinic run by RNS staffed with fulltime CNC diabetic educator and part time dietician and social worker. ***'No adult clinics - have to see private endocrinologists, but a staff specialist has recently been appointed and plans to run a transition clinic'***.

HNEAHS:

- John Hunter Children's Hospital (JHCH): 2 clinics per week with two endocrinologists, one full time and one part time CNC, diabetic educator, and allied health staff (dietician and social worker) ***There is a waiting list of 3 months***, with access to youth health team and a psychologist if required. Urgent cases given priority.
- Tamworth: diabetes clinic held by paediatricians 4 times a year and outreach clinics held 2 times a year. ***A young person's (YP) clinic is held quarterly with a waiting list of several months***. Priority is given to urgent and new cases. ***'Need for a social worker and psychologist'***.
- Armidale: outreach clinic held 2 times a year with MO, DE, and dietician. Patients managed by GP and paediatrician for rest of year and a SW is available. ***'Retention of a DE is limiting the service. No cover during leave. Young people tend to opt out during teenage years. Project with Division of GP whereby young people with T1DM are registered and called up by GP each year for review.'***

GWAHS:

- Type 1 only are seen at the Bathurst Hospital clinic which is held every 3 months and staffed by a consultant and educator. The CHW runs an outreach clinic at Bathurst and Dubbo twice a year.
- A monthly paed's clinic for under 18's is held at Orange diabetes Centre. There is a paediatrician, diabetes educator and part time dietitian. There is a waiting list for all disciplines but the diabetes educator and dietitian also run clinics. Urgent cases are given priority.
- Dubbo runs a monthly paediatric multidisciplinary clinic at Dubbo Base staffed by a paediatrician and visiting endocrinologists twice per year. There are two diabetes educators and part time dietician and psychologist. There is a waiting list of approx 8 weeks unless urgent.
- Broken Hill: There is one clinic every 3 months with a registrar who is in close phone contact with a consultant, a diabetes educator and dietician.

GSAHS:

- Wagga: Paediatric outreach clinic with MOs from SCH and CHW. ***Loss to follow up 'a big issue'***.
- Albury: no workforce information available. Staffed by a DE?

NCAHS:

- Coffs Harbour: an outreach clinic is held twice per year with 3 endocrinologists from JHCH and 1 from CHW. Local paediatricians also hold diabetes clinics once to twice per month. There is access to an adult diabetes educator and dietitian. ***Need a social worker***
- Ballina & Lismore: outreach clinic twice a year run by endocrinologists from JHCH and CHW. There is a local diabetes educator and access to local (non diabetes specific) allied health services (dietician, podiatrist and youth and family mental health worker) ***'Need more Diabetes Educators in Ballina'. The is currently only one full time diabetic specific staff member to provide services to all age groups in Ballina and the surrounding district***

- Grafton: outreach clinic twice a year at Ballina and Coffs Harbour by paediatric endocrinologists from JHCH and CHW (see Ballina and Lismore above). Type 1 and 2 clinics (not youth specific) are held at Murwillumbah, Tweed and Kingscliff. There are no local paediatric endocrinologists and access to bulk billing GPs able to manage young people with diabetes is difficult ***Lengthy travel for some to see endocrinologists at Coffs Harbour. Young people want access to a dietician. Many have depression but access to psychological help is difficult***

Endocrine Area Summary – 5 clinics

Children's Hospital Westmead:

- 1 clinic per week with specialists and nursing staff. *There is a waiting list of 2 months.* Private rooms are the alternative for those on the WL.

SSWAHS:

- Campbelltown: usually 1 clinic per week run by a staff specialist. No waiting list. Booked via SCH.

NSCCAHS:

- RNS: 3 clinics per week with 1.8FTE medical staff and part time nursing staff (all have other responsibilities) but no AH. This paediatric service is in an adult hospital. They see young people with a range of endocrine disorders such as hypothyroidism, growth problems, early or late puberty, obesity, Turners syndrome and Prader Willi. There is no waiting list'. ***More nursing hours required. Transition to GPs and adult endocrinologists'***

HNEAHS:

- JHCH: weekly clinic with 2 paediatric endocrinologists, a registrar, CNC dietitian, OT and physio. There is a 3-6 month waiting list. Conditions seen include Turner's syndrome, adrenal and pituitary problems, obesity and young people on growth hormone.

GWAHS

- Broken Hill: a clinic runs every fortnight for 1.5 days staffed by a consultant and nurses as needed. A small number of young people are seen.

Gastroenterology Area Summary – 4 clinics

Children's Hospital Westmead:

- *No patient data for 12-16 year olds or workforce data reported.*

SESAHS

- SCH: 3 clinics are held per month attended by 2 consultants a fellow and 2 registrars. A part time CNC is allocated to the clinic plus 2 dietitians. Service gaps include ***'Lack of nursing staff, social work support and psychologists'***

SSWAHS

- Campbelltown: 1 ambulatory paediatric clinic held 7 days per week with MO and nursing staff. One obesity MO clinic held every two weeks.
- Liverpool: run a clinic for Crohn's Disease 3 times per week and have small numbers of young people < 16 years. (see adult clinics)

HNEAHS

- JHCH: 1 clinic per month staffed by a specialist from SCH as there is ***NO paediatric gastroenterologist at JHCH***. There is a CNC and patients needing dietetic advice are referred to the general paediatric dietician. ***There is a waiting list of 3 months.***

Neurology Area Summary – 10 clinics

Children's Hospital Westmead:

- The Physical Disability (CP) clinic operates twice a week with 3 rehab consultants and registrar and fellow, 2 CNCs and OT and 2 physios. There is no waiting list.
- The Brain injury clinic operates once a week with MOs (rehab), 2 CNCs and OT and 2 physios. There is no waiting list.

SESAHS

- SCH: 1 cerebral palsy clinic is held per a week staffed by part time rehab specialists and a VMO orthopedic surgeon. There are no nursing positions. Part time allied health personnel include an orthotist, gait specialist, psychologist, speech pathologist, dietician and physio. Many children with CP do not attend the CP clinic but access services through neurology or orthopedic clinic as the CP service has only been operating for 3 years. A state wide study has revealed that only approx half of children with CP who would benefit being seen are currently reviewed by tertiary services. ***Need increased rehab specialist time, admin support and more allied health hours. Wait list is approx 3-5 months for the rehab specialist and up to 8 mths for gait assessment.***

SSWAHS

- Campbelltown: weekly neurology clinics attended by staff specialists. There is a WL of 1-2 months.
- Campbelltown: botox clinic held quarterly and staffed by 1 MO and 1 AH (physio). ***The service reported a shortfall in staffing.***

HNEAHS

- JHCH: MO clinics are held 1(registrar clinic) to 8 times per month (specialist) with nursing staff and a part time social worker. There is a ***waiting list of approx 6 months with private practitioners as the only alternative for uncomplicated case. There are no AH clinics.***
- Tamworth: a new outreach neurology clinic has recently commenced and will be held 3-4 times a year. Attended by a paediatric neurologist from JHCH, a CNC from JHCH and allied health staff from DADHC or Community Health. There is also a general paediatric clinic held which reported a small number of neurology patients.
- Muswellbrook: 3 neurology outreach clinics are held per year attended by a paediatric neurologist and CNC from JHCH and AH staff from DADHC and Community Health. ***There is a waiting list for new patients.***

GSAHS

- Albury runs a monthly acquired brain injury clinic attended by a rehab physician from Melbourne and part time OT, social worker, speech pathologist and neuropsychologist. A neuropsychologist from Sydney visits 4 x per year. Funding for a MO to visit twice a year has been applied for and the service has 'no extra capacity' – outreach services already provided to Deniliquin and Griffith.

Spina Bifida Area summary – 3 clinics

Children's Hospital Westmead:

- The Spina Bifida clinic operates once a week for 8 hours with MOs (rehab and staff specialists), RN and AH workforce. AH staff includes a physio, OT, SW, access to orthotist, orthoptist, dietician and neuropsychologist. There is no waiting list. Patients also attend developmental and therapy sessions as required.

SESIAHS

- SCH: clinic is run fortnightly with medical staff (paediatrician, urologist, neurosurgeon and orthopedic surgeon) 1CNC, 1 RN and AH staff -occupational therapy, physio, orthotics and social worker.

HNEAHS

- JHCH: 1 MO clinic per month held monthly with AH staff (OT and SW) but no nursing staff. *There is no waiting list but 'a need for RN to teach self-catheterisation'*. A transition program is being developed and need more hours for either a SW or OT to take on the role of case manager.

Genetics Area summary – 6 clinics

Clinics included 1 for EB (SCH – providing a state-wide paediatric service), growth, limb deficiency, connective dysplasia and neurogenetic clinics (all at CHW), and a muscle clinic at JHCH

Children's Hospital Westmead:

- Three growth clinics operates per month with 2 staff specialists, 1 reg and 1 fellow. There is one CNC but no AH staff. ***There is a WL with private rooms as the alternate service.***
- The limb deficiency clinic is run weekly and staffed by 2 rehab consultants, 1 registrar / 3 fellows. There is a FTE RN, OT, physio and 2 orthotics. No waiting list was reported.
- ***Connective tissue Dysplasia clinic*** runs a weekly clinic staffed by a rehab consultant, reg/fellow, 3 genetic consultants / 1 endo consultant. There is a CNC, one OT, 2 physios and 2 social workers. There is a waiting list.
- The **neurogenetics clinic** is held once a week. The main conditions treated are muscular dystrophy, myopathies, and neurofibromatosis type 1. The multidisciplinary team comprises MOs (2 FTE neurologists, 1 FTE geneticists, 1 Fellow and 0.25 rehab specialist), no nursing staff and part-time AH staff (OT, physio, Genetic counselor, Social Worker). *The waiting list is 'limited' with urgent cases prioritized.* Several other clinics (neuromuscular management and peripheral neuropathy) are available.

SESIAHS

- SCH: EB clinic is held once a month staffed by 1 paediatrician, 2 dermatologists, 1 geneticist, 1 gastroenterologist, nursing staff (1EB CNC and pain CNC) and AH (dietician, SW, OT, physio). There is a waiting list with priority given to urgent cases. ***More nursing hours are needed***

HNEAHS

- JHCH: outreach muscle clinic held once a month seeing muscular dystrophy patients, staffed by a specialist, and registrar from SCH. Two neurologists from JHCH can be seen outside clinic times. There is an outreach CNC and AH staff - OT, physio and dentition. There is no reported WL and the clinic is booked by SCH.

Other Clinics

Information was provided on the following services.

HNEAHS

- Immunology at JHCH
- CF, respiratory outreach and general paediatrics at Armidale
- General paediatrics at Tamworth

SWAHS

- Immunology and allergy - Blacktown
- Physical disability - St Joseph's
- General paediatrics - Liverpool

CHW

- Cystic fibrosis

GWAHS

- General paediatrics - Broken Hill

GSAHS

- Acquired and traumatic brain injury - Albury
- Fracture clinic at Albury

SSWAHS

- Renal, Haematology, General paediatrics, Cardiology, Immunology and Respiratory – Campbelltown
- Haemophilia /Thalassaemia – RPAH

NSCCAHS

- Immunology / rheumatology , allergy, haematology and ENT– RNS
- CF - Gosford

Appendix E

Adult workforce data summary for NSW outpatient clinics in 2007

Overview of adult workforce data

Data from a total of 156 clinics has been obtained, comprising 92 adult clinics and 64 paediatric clinics. A summary of workforce data for adult clinics, based on condition and Area Health Service, is provided below. The summary includes the 'top 5 conditions' of diabetes, other endocrine, spina bifida, cerebral palsy and gastroenterology. Haemophilia and metabolic genetics are also listed as there are gaps in outpatient services for young people with these conditions. In addition, a small number of other clinics are listed eg. general outpatients clinics which service young people.

All the data collected from service providers has been entered into an Excel database, located at the GMCT. Gaps in services are highlighted in the following sections, based on reported waiting lists and staff comments. The paediatric workforce summary is reported separately.

Diabetes Summary – 28 clinics:

SESAHS:

- Prince of Wales (POW): two clinics per week (one diabetes clinic at the diabetes centre for new patients and one OPD clinic for ongoing care). There is also a fortnightly Type 1 and insulin pump clinic. The diabetes clinic is staffed by a career medical officer, endocrine registrar and CNC but there is no allied health staff. The diabetes OPD clinic is staffed by a staff specialist and 2 endocrine registrars, OPD EN but has no Allied Health staff (AH). ***There is a waiting list (WL) for all clinics.*** Not all patient data is entered onto the clinic database. Some patients are seen in the clinic and then elect to go privately.
- Shoalhaven outreach diabetes service based at Nowra: outreach service provided by Illawarra Diabetes Service. Staffed by two endocrinologists, diabetic educator (DE) and dietician. Bookings taken by Wollongong.
- Sutherland: Diabetes educator (s), no MO. 'No endocrinologist on site'
- Illawarra Diabetes Service: 3 MO clinics per week and daily diabetes educator and dietician service available. ***'Many young people are seen by private endocrinologists in Sydney or are lost to the system'***
- St Vincent's: 1 diabetes clinic for new patients and one for existing patients is held weekly. ***'Most patients are older than 24 years of age'. Pump clinic has been discontinued.***
- St George: 1 clinic per week with 3 endocrinologists a resident and registrar, RN/EN, F/T diabetic educator at Diabetes Centre and AH staff (dietician, psychologist, podiatrist). ***There is a WL for all disciplines.***

SSWAHS:

- Royal Prince Alfred Hospital (RPAH): weekly Type 1 clinic with 1 medical officer, 2 RNs who specialize in Type 1 and a dietician. There is no waiting list. RNs see patients between clinics.
- Concord: 2 weekly clinics (one diabetes crisis clinic and the other diabetes / endocrine) with medical and nursing staff. No AH staff. ***No WL for crisis clinic but 6 weeks to 8 months for the other clinic.***

- Liverpool: 2 Type 1 clinics per month, with 2 FTE endocrinologists, 1 FTE registrar, 2.5FTE RNs, 1 dietician and social worker once per month. Urgent cases seen immediately and all others take 6-8 weeks.
- Bankstown: Young person's clinic held 1 per month and other adult clinics available. Staffing includes MO, DE, dietician and psychologist.

SWAHS:

- Blacktown: transition clinic held once per month with Diabetes Educators (DE) (no MO)
- Lithgow: DE service (no clinic). Patients also attend Bathurst outreach clinic which is held quarterly. *Need more RNs.*
- Auburn Diabetes Centre: clinic staffed by diabetes educator and CNC held 3 times a week. No medical staff. One dietician. **WL of 3 months.**
- Nepean: transition clinic held fortnightly with staff specialist, diabetes educator and dietician. Short WL of 1 to 2 weeks. DE is also available as an alternative service to those on WL.
- Fairfield: no information received on this clinic
- Westmead: transition clinic held weekly for 5 hours with an additional 5 hours pre and post clinic. Staffed by .3 CMO and 0.2 registrar, CNC, (1.1) dietician (0.3) and psychologist, (0.1) with access to podiatry and social work. No WL.

NSCCAHS:

- Royal North Shore (RNS): clinics are run daily Mon-Fri. There are 3 FTE endocrinologist and 2 part time + 3 VMO sessions each week. There are 2 FTE registrars, 4 full time and 2 P/T RNS, and a dietician does 2 sessions per week. WL up to 3 months to see endocrinologist. ***A new transition clinic run by an adult endocrinologist and paediatric CNC diabetes educator has commenced and runs monthly on the first Friday.***
- Mona Vale: 'no young people seen at this clinic'.
- Ryde: 1 clinic per week with DE, dietician and podiatrist. ***GMCT funding has increased this service'.***

HNEAHS:

- Newcastle Community Centre: Weekly Type 1 clinic with 2-3 endocrinologists, 2 CNCs and 1 dietician. Nurse's clinic held every 2 weeks with extra appointments made if needed. ***WL for 4-6 months for new patient. 'Need a psychologist and additional clinic with MO to reduce waiting list. ' and 'Nurses spending a lot of time following up non-attendees at YPC'.***
- Tamworth: (part of Community Health but attached to the hospital. All the RNs and dietician work in adult and paediatric clinics. 3 young people's clinics held a year with endocrinologist, CNCs (2.4FTE) and dietician (0.8FTE). ***WL of 4-6 months.*** 'Priority given to urgent patients and YP can attend other diabetes clinics.' Podiatry is available at Community Health and ophthalmologists attend 3 times a year. ***'Need another adult endocrinologist plus a social worker and psychologist'.***

GWAHS:

- Orange: 2 clinics per week (0.5 endocrinologist) with DE and dietician. ***WL for all clinics.*** There is an alternate service of DE and P/T dietician. Many young people move out of the area to attend university or seek employment.
- Dubbo: 1 clinic per week with DE plus monthly with endocrinologist. A dietician and psychologist are available 2 days per week for adults and paed. ***WL of 8 weeks***

and growing. No alternate service or AH clinics. 'More staff required', 'Not yet designated YP clinic.'

- Broken Hill: 1 consultant clinic per month with DE. No WL. A dietician clinic is available.
- Bathurst: YPC is held 4 days per year. 'No data kept once YP have left the paediatric clinic.' 'Attended by patients from Lithgow service'. **'Need a SW or psychologist.'**

GSAHS:

- Queanbeyan: 1 clinic per month with medical officer DE, dietician and nurse.

Endocrine Summary – 11 clinics including 2 combined with diabetes:

SESIAHS:

- POW: weekly clinic with 1 staff specialist, 2 registrars, 1 resident, 2 RNs/ ENs and admin support. WL for 2-3 weeks and private endocrinologists as an alternative.

SSWAHS:

- RPAH: 1 x 2.5 hr clinic per week with 5 FTE specialists, 3FTE RNs + admin support but **more clerical staff needed. WL for 2 months. 'YP reappear in late 20's after disappearing in transition period.'**
- Concord: 1 MO clinic per week with nursing staff. **WL 6 weeks to 8 months.**
- Campbelltown: 1 MO clinic per week (no nursing) commenced in late 2007. No WL.

SWAHS:

- Blacktown: 1x 4 hr clinic per week staffed by a consultant, registrar and one nursing staff per week and admin support (no AH). Waiting list for new patients.
- Nepean: 2x 2hrly clinics per week staffed by a consultant and registrar. No nursing or AH staff. No WL. A dietician is available.
- Westmead: weekly 3.5 hr clinic with 1.6 FTE staff specialists + VMO session/week and two registrars. There is also 0.4 FTE nursing staff per week but no allied health

NSCCAHS:

- Royal North Shore (RNS): Clinics are run daily Mon-Fri (4 hrs am and pm). There are 3 FTE endocrinologists and 2 part time + 3 VMO sessions each week. Patients have a range of conditions such as thyroid disease, polycystic ovary disease, growth hormone abnormalities, pituitary disease and Addison's disease. There are 2 FTE registrars, 4 full time and 2 part time RNS. A dietician does 2 sessions per week. WL up to 3 months to see endocrinologist and there is admin support. Waiting list is approx 3 months to be seen by an endocrinologist.

HNEAHS:

- Endocrine clinic is held weekly (3 hrs) staffed by 3 endocrinologists and 2 registrars. No other information provided.

GWAHS:

- Broken Hill: 1 clinic is held 1.5 days per month on a fortnightly basis. Staffed by a consultant and nurses if needed. **WL approx 3 months.** A dietician and other allied health staff are available at Broken Hill Hospital.

Gastroenterology Summary – 10 centres:

SESIAHS

- POW: 5 half day clinics per week staffed by a staff specialist and part time VMO. No allied health; 0.6 EN + admin support. No WL for urgent cases. 2 weeks if not urgent. Dietician is available as needed.

SSWAHS

- RPAH: 1 x 4.5hr clinic per week with senior consultant, 2-4 registrars and 1 RMO. One FTE RN and admin support **but need more with experience in specialty**. No AH. No WL for urgent cases and **3 months for new cases**.
- Concord: 7 clinics per week 4 x 2hrs, 2 x 3hrs and one full day clinic. Staffed by specialists and nursing staff. No WL kept.
- Liverpool: 9 to 10 clinics per week with MO, nursing and dietician. **WL up to 6 months. 'No alternative public services'**

SWAHS

- Nepean: 2 x 2 hr consultant + registrar clinics per week. No allied health - nurse is available if needed. At most, 2 weeks wait. 3 x 2hr liver clinics per week. No WL
- Westmead: Weekly 3hr clinic + 2hrs every 2nd Friday to shorten list. Consultant + 1-2 registrars/residents. One FTE RN. **WL of 3 to 4 months with only private gastroenterologists as alternative.**

NSCCAHS

- RNS: 1 x 4hr clinic per week staffed by 4-5 doctors and 2 RNs with admin support. **WL of 6 weeks for new patients and 2-3 weeks for review**. Urgent cases given priority. Patients can be referred to AH clinics at RNS.
- Gosford: 2 x 3.5hr clinics run by specialist twice per week and full day clinic twice per week. No nursing staff but sometimes a registrar attends. **WL of 6 weeks for review patients.**

HNEAHS

- JHH: Clinics held 3x per week. 3 staff specialists + 1 advanced trainee and rotating registrar Tuesday and Wed, one staff specialist Thursday. No dedicated nursing staff. There is a gastro liaison service for advice and education Mon-Fri. Dietician (3 hrs) and SW available if needed. **WL of 6 months.**

GWAHS

- Broken Hill: 1 full day consultant clinic held monthly and one every two months. Nurses available if needed. **WL of 3 months**. Dietician clinic available

Neurology Summary – 13 clinics:

SESIAHS

- POW: 2 x 3hr neurology clinics per week staffed by neurologist and OPD nurse (no specialized nursing or AH). Access to OT, SW, physio and neuropsychologist. **WL of 4 to 9 months. Insufficient medical and clerical staff. Need clinical co-ordinator, 3 hours for MO follow-up and access to a psychiatrist.**
- POW: Neurology / epilepsy clinic held x 2 per week staffed by neurologist, Epilepsy Fellow, VMO neurologist and neurosurgeon 1-2/month (not funded). There is also a

nurse educator (not funded) and part time health services manager. **Average waiting list is 4-6 months.**

- POW: neuromuscular clinic (see mainly dystrophies) 2 MO clinics per month with CNC, OT and physio. Access to AH clinics for seating, hand, physio and hydrotherapy clinics. **WL up to 2 months. Need clinic co-ordinator 1 day per week and extra 2 hours / MO /clinic for completion of forms, tests etc**
- Illawarra service: Cerebral Palsy (CP) – **MO clinic discontinued. 'No funding for transition care'**
- Wollongong: CP service x 1 per week. **MO clinic discontinued. No funding for transition care'**

SSWAHS

- Campbelltown :1 clinic per week with 2 staff specialists (no nursing or AH). No WL. **'Additional staff required'**
- Concord: 1 x 2hr neuromuscular clinic every 2 weeks (no nursing or AH). No WL kept.
- Liverpool: 3 full day brain injury clinics per week with nursing staff, orthotist, OT and physio available. MO available? **WL up to 6 months. 'No alternative public services'**

SWAHS

- St Josephs Hospital: weekly clinics for young people with cerebral palsy including a spasticity clinic and rehabilitation clinic for longer term management. 1 clinic per week with nursing staff and access to physio, OT, SW and speech therapy clinics. **WL of one month for all disciplines.**
- Westmead: 1 physical disability clinic per week with specialist, physio and OT (no nursing staff). No WL. There is a need for a disability registrar at WMH to cope with increasing numbers of pts with disabilities, not only to outpatient clinics, but also inpatients.
- Monthly CP clinic at Westmead. Adults with CP need a rehab physician to take on ongoing management as well as allied health support. New treatments require attention to funding.

NSCCAHS

- RNS: No information provided.
- Gosford: 2 clinics per week staffed by a neurologist (no nursing or AH staff). **WL of 4-6 weeks.**

HNEAHS

- JHH: 6 MO clinics per week. **WL of 2 to 9 months depending on MO. Alternative to WL is private.**
- Maitland: 1 MO clinic per 2 weeks (no nursing or AH staff). Not known if a WL.

GSAHS

- Albury: brain injury: 1 clinic per month attended by rehab physician, nursing, speech therapy, OT and SW. Attended by a neuro-psychiatrist every quarter. Provides outreach service to Griffith and Deniliquin. Not stated if there is a WL. **'Staffing levels not adequate due to size of region'.**

Spina Bifida Area summary – 4 services

SESIAHS

- POW: x 1 clinic (4 hrs) per month (*with urgent patients seen in the spinal clinic in between spina bifida clinics*) **WL of 1 to 3 months. No other staff allocated to this clinic which is added onto full spinal unit caseload of senior staff specialist. No available resources.** Referral to Orthotics, local physiotherapy service or spinal CNC for advice on intractable bowel and bladder problems. In addition to AH services, specialized medical services required include urologic services, neurosurgical services, and multidisciplinary team to treat pressure areas. Patients are difficult to treat in general wards due to specialist care required. A significant proportion have severe complications and spinal units should receive enhanced services to treat such patients

SSWAHS

- RPAH: 1 full day clinic per month staffed by **paediatrician** and 1 nursing staff (8 hours). ***There is a WL for services. 'A dedicated SB clinic is essential to SB patients'. 'Staffing levels are not adequate. Need one dedicated CNC for adults and AH services for OT, physio and social work. Also need community follow-up to address cognitive issues which often prevent effective interventions.'***

SWAHS

- Westmead: 1 x 3hr clinic per month with 2 consultants and 1 registrar, 1 nurse, no AH. WL - time not stated. ***Lack of public services in urology, neurosurgery and orthopaedics.*** Referred to private allied health services except for OT at Northcott Disability Services.

HNEAHS (no specific adult spina bifida clinic)

- All patients > 18 yrs are referred to an adult rehab specialist at JHH and to their GP as case manager. The Spina Bifida clinic has transition meetings monthly to discuss young people who need to transition.

EB, Neurogenetic and Metabolic Genetic Summary – 4 clinics:

- Two EB clinics were surveyed (POW and St George), one neurogenetics (RNS) and one metabolic genetics clinic (Concord). Information on rare genetic conditions was also obtained from Professor Sillence at CHW.
- There is no CNC at POWH educated in EB management and the person currently employed at SCH is unable to take on the EB clients due to existing work load. Allied Health support at POWH is inadequate.
- No workforce data was available from St George. They have an EB specialist who runs a clinic but no other infrastructure.
- A new metabolic genetics clinic opened at Westmead in May 2008. No data was available but it is predicted that approximately over 200 patients aged over the age of 16 years will be transferring from the paediatric clinic at CHW.

Other services:

Information was collected on the following services but has not been reported on:

- RNS: allergy
- Gosford: CF
- St Vincent's: general outpatients
- RPAH: haematology
- Campbelltown: Immunology
- Liverpool: brain injury
- Broken Hill: haematology
- JHH: immunology
- Blacktown: immunology
- St Joseph's at Auburn: general rehab
- Westmead: haematology, allergy, immunology and immune deficiency

Appendix F

TRANSITION CARE FOR YOUNG PEOPLE WITH CHRONIC ILLNESS AND DISABILITY SUMMARY OF EFFECTIVE MODELS AND GAPS IN SERVICE

CONDITION / TYPE OF CARE REQUIRED	LEVEL OF ADULT HEALTH SERVICE NEEDED
1. Mainly single specialist /ambulatory setting	Tertiary service/ other hospital/ primary care
asthma	Most young people with asthma can be managed on an ambulatory basis in primary setting by GPs. A relatively small number with moderate to severe asthma, require specialist review and management but not necessarily at tertiary hospitals. All AHS should have an appropriate ambulatory asthma service. <i>Existing services appear adequate but more public clinics for patients with severe asthma would be ideal.</i>
epilepsy, congenital heart disease, HIV/AIDS, chronic eye conditions	These conditions require specialist review and management on a regular basis – minimum yearly. This might be done privately or in a public ambulatory facility. <i>Existing services appear adequate.</i>
2. Multidisciplinary team/ ambulatory setting	
Muscular dystrophy, peripheral neuropathy, spina bifida, cerebral palsy, rheumatology, developmental disability, Epidermolysis Bullosa (EB)	Need specialist clinics at locations where the majority of these young people are managed. 3-4 services currently exist. The rehab model could be applied to this group eg Port Kembla spina bifida and disability service. Working groups have been established to define models of care further for these conditions. <i>More services are required. A state-wide coordinated model of care has been proposed for spina bifida</i>
thalassaemia and haemophilia	Require clinics associated with major treatment centres – currently 3 in Sydney and 1 in the Hunter. <i>More clinics are needed to cope with increasing numbers.</i>
cancer and late effects of cancer	Senate Enquiry 2005 made several recommendations re young people with cancer and specialist cancer services are reviewing transition models and these recommendations are currently being implemented. <i>There is a problem with adult patients being seen in paediatric facilities</i>
diabetes	One model suggested by the diabetes working group is for young people leaving paediatrics to attend a coordinated transition clinic for several years. Several such clinics currently exist eg Westmead and Nepean but <i>more public hospital facilities are needed</i> as adult diabetes services are overwhelmed with type 2 DM
metabolic and rare genetic disorders	<i>Need one specialist adult tertiary centre. Clinic has commenced at Westmead – June 2008</i>
spinal injury, brain injury (long term care)	Require specialist units at dedicated sites such as Royal Ryde Rehabilitation Centre and Liverpool Brain Injury Unit for assessment and monitoring on a regular basis. <i>Existing services seem adequate</i>
3. Complex multi-disciplinary specialist care with a large inpatient care component	
Cystic fibrosis, chronic renal failure, liver disease, gastrointestinal disorders, auto-immune conditions, complex neurology.	Mainly require tertiary care and need not be restricted to one site. Appropriate locations depend on numbers of patients, existing services such as dialysis and transplant. Number of facilities required is dependent on number and distribution of patients.

Prepared by Lynne Brodie, Transition Network Manager, May 2007: updated June 2008