



HUNTER NEW ENGLAND
NSW HEALTH



Kaleidoscope (GNS) & GMCT

Allied Health Transition Project Final Report - December 2007

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2. Letter to Director of Allied Health.

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09 January 2006

David Rhodes
Director of Allied Health
Hunter New England Area Health Service

Dear David,

Re: Transition of Occupational Therapy and Physiotherapy Services from Adolescent to Adult Teams

The transition of adolescents to adult services is becoming a dominant issue, as the rate of children with chronic health conditions passing from paediatric health care services to adult health services is increasing.

Currently children with chronic medical conditions access multidisciplinary team based services on a regular basis through John Hunter Children's Hospital. This allows access to a variety of services including medical professional consultations, occupational therapy, physiotherapy, speech therapy, nutrition and dietetic services, social work, psychology, and nursing services. These teams offer assessment, therapy and monitoring of children's conditions and their needs, and provide appropriate intervention when necessary. Such services are provided to children with conditions from the following diagnostic groups: Spina Bifida, Acquired Brain Injury, Muscular Dystrophy, Juvenile Chronic Arthritis, chronic neurological conditions including Charcot-Marie Tooth disease, connective tissue disorders, oncology conditions, limb deficiency and amputees, complex orthopaedic conditions including scoliosis and arthrogyrosis, and chromosomal disorders. Unfortunately, there is not a consistent service to which these client groups can be transitioned to maintain the assessment and management of their ongoing needs, except in the areas of Spina Bifida and Acquired Brain Injury. Upon reaching 18 years age, adolescents with Spina Bifida access the Spinal Cord Injury Service, and those with Acquired brain injuries access the Community Brain Injury Team.

The importance of transition between paediatric and adult services is well recognised, particularly due to the significant differences noted between these types of services in terms of treatment philosophies, goal setting and client-focussed care. Paediatric services are often multidisciplinary, parent driven, supportive and holistic. The team of professionals will be engaged to provide a team focus to identify and manage the child's overall condition and various medical, physical and psychosocial needs.

Conversely, adult medical and therapy services within the Hunter New England Area tend to focus on isolated discipline-specific goals, and the provision of services to address these goals one at a time. There is also a strong client-focussed model of care whereby the young adult is encouraged to take responsibility for their condition and therapy, with a resultant decrease in parental / family involvement.

It is acknowledged that paediatric health services need to start preparing young adults for the transition process: from a family-centred and professional-directed therapy approach to a service that has a more self-directed focus. Paediatric services need to encourage the empowerment of these young adults in the management of their conditions, and provide them with the information and skills required to master this new environment.

However, appropriate services for these types of clients are lacking following discharge from paediatric services. The transition process, timing of service transfer, and place to which service is transferred is inconsistent, and determined by individual client needs, their individual therapist, and their General Practitioner, due to the absence of a case manager or Paediatric Rehabilitation Specialist. Where possible, therapy staff aim to refer these clients to whatever service appears most appropriate to their current level of needs. At discharge from paediatric services, clients are provided with a discharge report outlining their condition, past and current management and proposed treatment goals. The emphasis is then placed on the client to find individual therapists to address their therapy needs. The following list outlines some of the current practices for referral from paediatric to adult services:

- Spinal cord injury or spina bifida clients to the Spinal Cord Injury Service
- Acquired Brain Injury clients to the Community Brain Injury Team
- Clients requiring palliation to Palliative Care Services
- General orthopaedic complaints such as scoliosis and chronic back pain to outpatient physiotherapists at the Royal Newcastle Hospital or Belmont Hospital
- Hand injuries/conditions to the Hand therapists at the Royal Newcastle Hospital
- Children with equipment needs to the Occupational Therapists at PADP for assessments
- Referral to individual Allied Health professionals where available.
- Referral to an adult Rehabilitation Specialist with the expectation that this may facilitate referral to other appropriate services

It has been identified that there is currently not an appropriate team-based service for the ongoing management of these complex young adults. Current referral trends and transition processes are inconsistent, inequitable and do not address the complex and varying needs of these clients. Furthermore, current adult rehabilitation services provide poor motivation for younger clients due to the elderly nature of the population accessing these services.

The identified priority for health services at this stage is the appointment of a Paediatric Rehabilitation Specialist to facilitate the consistent and timely transition and referral to Allied Health services for young people with chronic conditions. The requirement of a transition team to facilitate the transition process from paediatric to adult services is recognised, in order to provide children with the appropriate skills required to negotiate their health care needs in an adult-based service environment. Furthermore, the development of an appropriate team-based service addressing the complex and diverse needs of young people with chronic conditions and containing appropriate facilities to provide ongoing motivation for long term rehabilitation is paramount. Young people with chronic complex conditions require a rehabilitation setting that is age appropriate and enables them to mix with clients of similar ages to provide them with support and motivation.

It is acknowledged that the role of paediatric health staff in the transition of these young adults to adult services is not optimal at present, but is adversely affected by the lack of identified services to which these clients may be appropriately transitioned to. Identification and confirmation of such services for this client group would enhance the consistency, timeliness and effectiveness of transition processes Thank you for your consideration of this issue. If you require further information regarding the issues outlined in this document or would like to discuss this further, please do not hesitate to contact us on (02) 4921 3700.

Yours sincerely,

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 Head of Department
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EXECUTIVE SUMMARY for the GMCT TRANSITION PROJECT BASED IN THE HUNTER March – December 2007

Kaleidoscope (GNS) Allied Health Transition Project in the Newcastle Area.

Background

Discussions in 2006 between the GMCT Transition Coordinator, Northern Area, Hunter New England Area Health Service (HNEAHS) and clinical staff from the John Hunter Children's Hospital (JHCH) Allied Health (AH) services highlighted the need for a formal transition process for young people requiring ongoing therapeutic care as an adult. Paediatric AH services across all disciplines but particularly Physiotherapy and Occupational therapy were reporting an increase in the number of young people with chronic medical conditions accessing their services each year. This translates into an increasing number of young people needing to be transitioned into equivalent adult services AH every year. Anecdotally, an unknown number of clients are failing to transition to adult services due to lack of awareness, information and confidence as well as the significant differences that exist between paediatric and adult services. It is assumed that clients failing to successfully transition fall within the diagnostic groups currently without a formalised transition pathway i.e. Muscular Dystrophy, Juvenile Chronic Arthritis, chronic neurological conditions including Charcot-Marie Tooth disease, connective tissue disorders, oncology conditions, limb deficiency and amputees, complex orthopaedic conditions including scoliosis and arthrogyrosis, and chromosomal disorders. Diagnostic groups including Diabetes, Cystic Fibrosis, Spina Bifida and Head injury have clear transition pathways in place due to the presence of equivalent paediatric and adult multidisciplinary clinics, which ensure continuity of service.

A submission for one off funding for a 6 month part-time Kaleidoscope AH Transition Project Worker was ratified by The Greater Metropolitan Clinical Taskforce's (GMCT) Transition Program in 2006. Recruitment to the position occurred in March 2007.

Specific Aims

- Determine current trends in transition for young people with chronic conditions in the Hunter.
- Obtain both clinician and consumer perspective on the transition process as it currently stands in the Hunter.
- Research what resources (within health and the community) are currently available to young people who require ongoing Allied Health intervention after they leave the paediatric service.
- Complete a literature review to determine current trends and key ingredients for successful transition.
- Identify gaps in service provision for this population and make recommendations to address them.

Method

- Data: information was collected on the number of young people requiring transition from AH services in JHCH.
- Consumer input: young people and their families were surveyed about their transition needs using questionnaires and phone surveys. Adult and paediatric clinicians were also surveyed.
- Meeting conducted with AH heads of discipline at JHCH.
- AHMIS data was collected from 2002-2007 for both young people (16-24) and adults (24+) accessing Adult AH outpatient services.
- File audit completed to review documentation and information sharing regarding transition.
- Current transition resources were reviewed and modified
- Gaps in service provision were identified and short term and long term recommendations were made to address identified gaps.

Outcomes

a. Data Collection

According to the Transition Care Clusters Document for HNEAHS, 172 young people required transitioning to appropriate adult services.

b. AHMIS Data

- AHMIS data indicated increasing numbers of young people (16-24) accessing adult AH across all disciplines.
- Significant increase in number of adults accessing AH over the last five years further stretching available AH outpatient services.

c. Consumer Input

300 questionnaires were mailed out with 20 appropriate questionnaires returned which revealed the following:

- i. Only 30% reported that AH clinicians had discussed the transition process with them.
- ii. Of this 30%: 50% did not know about increased/ changed roles and responsibilities in adult services, 66% indicated they had an appointment with an adult services, 83% indicated that they had been told of the differences between paediatric and adult AH services, 66% knew where the adult AH services were, 83% knew when transition would occur. However, 66% had not been given any information about what services they would transition to.
- iii. The key areas in which client and consumers wanted information to assist with transition were; differences between adult and paediatric Allied Health services, what is transition and when does it occur, financial and medical decision-making, Centrelink and government entitlements, and a young person's role and responsibilities during transition.

d. Clinician Input

5 meetings were held with heads of discipline with fluctuating attendance. Surveys were mailed out to paediatric and adult AH clinicians with 8 paediatric surveys and 1 adult survey returned. The following was determined:

- i. No formal transition pathway for AH clinicians working with this population.
- ii. No paediatric/youth rehabilitation specialist to provide case management throughout transition and early adulthood.
- iii. Lack of appropriate adult AH services for paediatric clinicians to transition clients with complex disabilities to.
- iv. Reluctance to transition complex clients due to lack of services. In some cases clinicians did not transition clients and continued to provide intervention to young adults as old as 20.
- v. Concerned that GPs are being asked to be case managers for this population with minimal information on the AH service needs of this population.

Service Gaps

- This project has identified a distinct lack of developmentally appropriate AH services in the Newcastle area available to young people with chronic conditions/illnesses. This lack of appropriate services to transition clients to directly results in transition either not occurring i.e. paediatric services continuing to provide an active services to young adults or poorly planned/coordinated transition. The lack of services available is exacerbated by the rigid referral criteria, which exists for accessing adult AH services and the ever-increasing number of adults 24+ accessing this service.
- Lack of case management services available for young people with chronic medical conditions.
- Lack of information sharing on transition between paediatric and adult clinicians.

Resources and Education

- AH guidelines for transition were developed from existing GMCT Transition resources and the Interim Transition Guidelines Policy for HNEAHS, Kaleidoscope Children's Services. Guidelines were preferable to developing a structured transition plan or pathway due to the diversity inherent in this population, which will always require differing levels of support and guidance from clinicians. It is hoped that these guidelines will enable clinicians to develop their own discipline specific transition processes and be flexible enough to meet the needs of their individual clients.
- A map of Adult AH Outpatient services was compiled for the Hunter area as a guide for clients, carers, clinicians and GP's. It is anticipated that this will be ongoing into 2008.
- A List of appropriate Non-Government Organisation's in the Newcastle area was compiled for clinicians to refer young people to for assistance with life skills, vocational issues/endeavours, education and training options.
- A short cut from HNEAHS intranet site to GMCT Transition Care website was implemented to assist clinicians accessing existing Transition Care resources for professionals and consumers.

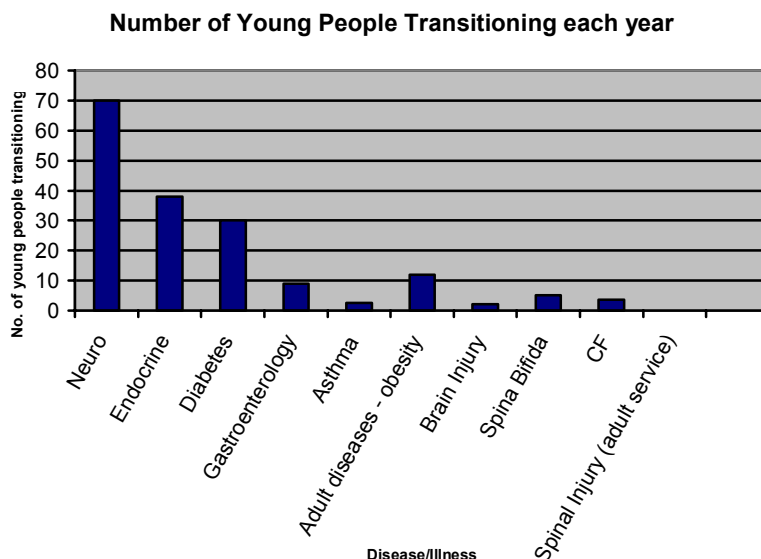
Recommendations/Future Challenges

- Promotion and support of the transition guidelines to enable implementation and adaptation for all disciplines at JHCH.
- Increased funding for AH to provide a more comprehensive service to young adults in the Hunter.
- Obtain further support at a management level to assist and encourage clinicians to participate in future projects which require a strong collaborative input from both adult and paediatric services to be successful and promote change within HNE Health.
- Implementation of a flagging and tracking system to collate accurate statistics on frequency and range of services accessed by young people with chronic conditions including emergency and inpatient admissions.
- Creation of an Allied Health Transition Care Forum to meet regularly to promote the transition process, discuss current resources and needs of the transition population and continue the education process for clinician's on the management of this complex population.
- Investigate the role of the GP in case management for this population. What support, resources and information do GP's currently have and need to participate in the transition process?
- Establishing a young adults complex disability clinic in Newcastle similar to successful clinics currently operating within Victorian Health. A complex Disability clinic would involve Allied Health professionals specialising in the management of young people with regard to developmental and psychosocial issues, cultural and lifestyle factors. The clinic would also provide medical consultation by a young persons rehabilitation specialist. Such a clinic is ideal in addressing the gaps in service provision and promoting continuity of service and case management principles for this complex and heterogeneous population.

3. Background

Discussions in 2006 between the GMCT Transition Coordinator, Northern Area, Hunter New England Area Health Service (HNEAHS) and clinical staff from the John Hunter Children's Hospital (JHCH) Allied Health (AH) services highlighted the need for a formal transition process for young people requiring ongoing therapeutic care as an adult. Physiotherapy and Occupational Therapy services identified an increase in the number of children with chronic conditions accessing their services and a subsequent increasing need for investigation of their transition process within Allied Health services in the local area. Anecdotal information indicated that many of these clients were not accessing adult services due to lack of awareness, confidence and the significant differences between the paediatric and adult Allied Health services in the area. It was identified that there was no clear transition pathway for young people within the following diagnostic groups; Muscular Dystrophy, Juvenile Chronic Arthritis, chronic neurological conditions including Charcot-Marie Tooth disease, connective tissue disorders, oncology conditions, limb deficiency and amputees, complex orthopaedic conditions including scoliosis and arthrogyposis, and chromosomal disorders. Young people with Spina Bifida and Acquired brain injury on the other hand, have clear transition pathways in place, accessing the Spinal Cord Injury Service and Community Brain Injury Team respectively.

Information gathered from the Transition Care Clusters Document for HNEAHS indicates the following is occurring in the area. Data collected from the JHCH outpatient (OP) clinics indicates that a significant number of young people are requiring transition from paediatric services on a yearly basis. Due to the long term and significant health concerns of this population and the impact of lifestyle and developmental change, it is expected that they will require ongoing Allied Health intervention as adults. Allied Health intervention focuses on improving and developing the client's individual skills, access to the community, mobility and vocational and educational options.



Currently, clients presenting with Spina Bifida (5), Cystic Fibrosis (3.5), Spinal Cord Injury (0), Brain Injury (2) and Diabetes (30) have a clear transition pathway in place to ensure continuity of services. The following diagnostic groups however are unaccounted for in terms of clear documented transition processes towards a developmentally appropriate clinical service; Neurology (70), Endocrine (38), Gastroenterology (9), Asthma (2.5) and Adult diseases (12). In total 131.5 clients are discharged from JHCH OP AH services to developmentally inappropriate and already stretched existing adult AH service providers. Given the complexity of these cases with regard to multifactorial medical issues, developmental skills and age, cognitive functioning and client-carer relationships / dependency, it is obvious that the existing adult AH services will not be able to offer the necessary time or long term commitment to manage this complex caseload. This is supported by findings from the recent Hunter Region Neurology Transition Project conducted in HNEAHS at JHCH in 2006, where it is reported that Adult Allied Health services:

- ii. Lacks resources for the general adult population, let alone the young people with complex disabilities.
- iii. There is a strict criteria set down for accessing services that often make it difficult for the patient to obtain a service.
- iv. There is no pivotal person that can facilitate the access to these teams and often too much time is wasted trying just to find out whom to contact for a specific issue.
- v. There is a wide gap between what is available as an inpatient versus outpatient.
- vi. Families have reported that there are some good private Allied Health personnel but they are difficult to find and that 'most only want to deal with sports injuries etc that pay well, not disabled people'.

From: Hunter Region Neurology Transition Project, Final Report – September 2006, Gilda DiCesare

Given this data and existing services, in a period of 5 years it could be assumed that an average of 657.5 young people with chronic conditions may be having difficulty accessing appropriate or assistive AH services in the Newcastle area. Considering the scope of services and therapy options provided by AH professionals, the absence

of these appropriate services may adversely affect the client's health and well-being in terms of their ability to develop the necessary skills to manage a life long illness / condition. This could potentially result in an increase in emergency and inpatient hospital admissions. It would also decrease their potential to a) pursue opportunities regarding vocation and employment, b) continue to develop cognitive and functional living skills and c) facilitate healthy lifestyles.

A submission for one off funding for a 6 month part-time Kaleidoscope AH Transition Project Worker was ratified by The Greater Metropolitan Clinical Taskforce's (GMCT) Transition Program in 2006. Recruitment to the position occurred in March 2007.

Description of Paediatric AH Services at John Hunter Children's Hospital

The JHCH offers the following specialised AH services to the local community and HNEAHS:

- Physiotherapy
- Occupational Therapy
- Speech Pathology
- Dietetics
- Social Work
- Psychology

The term "specialised" indicates that some of the services offered may be assessment and / or consultative only with transfer back to existing community services for follow up therapy. However, the majority of the services offered are intensive therapy for high needs children and adolescents who present with underlying chronic conditions.

The majority of clients accessing the JHCH AH services can be divided into two general categories; those with a chronic condition requiring ongoing consultation, therapy and/or support or those requiring some short term outpatient services following an admission to the children's hospital for management of an acute injury / illness. Referrals are received through specialised clinics, GPs, direct from the community and following hospital admission.

The project focused on the outpatient AH services offered at the JHCH for children and adolescents with chronic conditions including: diabetes, other endocrinological diseases, spina bifida, neurology and gastroenterology.

4. Literature Trends

The current literature surrounding transition for young people to adult services shows the emergence of key issues for Allied Health professionals, consultants and consumers.

"It is this author's opinion, and that of Betz (1998) and White (1997), that transition to adulthood does not begin at the age of 16 or 18 or upon entry into agencies providing transition services but earlier within the context of the child and family's development as they digest their own definition of the child's disability." (Luther, 2001).

A literature review using CIAP OVID databases yielded 16 relevant articles for this project. The majority of the articles reviewed used processes such as consumer/clinician surveys and focus groups to evaluate existing services and service needs. The following trends were found within the articles reviewed:

- i. Transition needs to be planned and coordinated for it to be successful and that planning needs to occur early in the clients adolescent years.
- ii. Timing of transition should be individualised according to other important transitions such as schooling, the psychological and cognitive maturity of the client as well as the severity and stability of the disease should also be considered.
- iii. Clients and carers need to be encouraged to become involved with care-decision making prior to transfer to adult services.
- iv. Lack of information provided to clients and families on the process of transition and available adult services sets them up to fail within the Adult medical system.
- v. Where appropriate, clients need to develop their own independence in managing their conditions prior to transfer to adult services.
- vi. Health professionals need education and training in how to transition their clients successfully.
- vii. A key coordinator or case manager is considered best practice in successfully managing the transition process.
- viii. Multidisciplinary services for young people with chronic conditions need to be developed to manage this emerging complex caseload. These services need to be developed with regard to the caseloads age, developmental skills, cultural and lifestyle needs. It is not appropriate for these clients to be managed by a paediatric service when they are no longer children.
- ix. Success of existing transition services is not limited by participation of the young adult and their family but rather by the health service itself in particular adequate funding of the service.
- x. Addressing psychosocial and educational/vocational needs is as important as addressing medical needs.
- xi. Strong interagency links are essential for transition care.

See the literature review in Appendix 1 for more detailed findings.

5. Project

a. Objectives

- Gain a clear picture of the young people attending the JHCH Allied Health services
 - i. Condition
 - ii. Ages
 - iii. Therapy received and ongoing needs
- Research what resources (within health and the community) are currently available to young people who require ongoing Allied Health intervention after they leave the paediatric service.
- Obtain consumer input
 - i. Talk with young people and their parents/carers about their needs during transition
 - ii. Compile their stories
- Identify gaps that exist in service provision for young people that require transitioning to adult Allied Health services
- Work with consumers, paediatric and adult clinicians to develop a transition process for young people attending Allied Health services at JHCH, including recommendations to reduce ongoing gaps in service provision.
- Determine trends if any for numbers of young adults accessing adult outpatient services over the last five years.

b. Steps Taken to Meet Objectives

- Data was analysed from the JHCH data base system, AHMIS, to identify appropriate clients and generate a mail out list. The mail out consisted of a consumer questionnaire designed to ascertain the consumers' current understanding of transition, experiences with transition and thoughts on how to improve existing transition processes in the Newcastle region. However, difficulties were encountered interpreting the AHMIS data as each client could not be identified by a specific chronic condition (principal diagnosis) but was instead was identified by therapy provided by AH professionals only. Therefore the data collected was not truly reflective of the numbers accessing AH services. The final mail out list was determined to be the most accurate given the limited information and all clients on the list met the following criteria:
 - i. Attended AH OP services at JHCH in the period between Jan 06 – Jan 07
 - ii. Attended 2 or more AH services as per AHMIS entries
 - iii. Aged between 14 – 22 years
 - iv. Therapeutic diagnosis was potentially indicative of an underlying chronic illness or condition
- The needs of young people and their parents during transition was investigated through the following measures:
 - i. Questionnaires
 - ii. Phone interviews with client and carers currently accessing AH services at JHCH who indicated a willingness to participate in the project:
- The needs of the clinicians were investigated through:
 - i. Direct meetings with relevant heads of AH disciplines at JHCH
 - ii. Clinician surveys were sent to all AH teams involved with the transition process (included adult and paediatric services)

- Review of current literature was conducted to identify:
 - i. Current trends in the area of transition for this population of clients
 - ii. Existing transition processes
 - iii. Population issues
 - iv. Clinician issues
- Reviewed existing GMCT Transition Care resources for possible use in or adaptation to this project.
- Evaluated data collected from consumer and clinician questionnaires and interviews with respect to current literature.
- Developed appropriate AH transition resources for clinicians, including:
 - i. Guidelines for transition process in AH paediatric services at JHCH
 - ii. AH adult services map in GNS area including referral methods and client selection criteria to assist paediatric clinicians provide accurate adult service information to clients and carers.
- Compiled an accurate map of Adult Allied Health outpatient services available in the Newcastle area for young adults to facilitate easier access to appropriate services. To be distributed to GP's and NGO's, Allied Health clinician's at JHCH at the conclusion of the project with the assistance of the Hunter Urban and Rural Division of General Practice.
- Data was analysed from the JHH and RNC database system AHMIS to determine trends in number of young adults (16-24) accessing adult AH outpatient services from 2002 til now. Again difficulties were encountered due to the limitations of the system, which fails to identify patients through principal diagnosis (see above). Data was also acquired on total number of clients accessing adult AH services over the last 5 years.
- A small file audit was conducted to investigate how previous clients had been transitioned to adult services as documented in medical records. Data was collected regarding documentation of transition, method of information sharing between adult and paediatric clinicians and timing/coordination of transition.
- Recommendations based on identified gaps in service provision, evaluation of data and literature trends.
- Recommend future areas of study based on results of investigations.

c. Key Data Collection Results

- i. **Client and Carer Questionnaire**
 - 300 mailed out
 - 20 appropriate questionnaires returned

These key findings were elicited from the client and carer questionnaires (data graphs are in Appendix 2).

- Only 30% reported that AH clinicians had discussed the transition process with them.
- Of those to whom transition had been discussed; 50% did not know about increased/changed roles and responsibilities in adult services, 66% indicated they knew when their appointment with the adult services was and had other AH clinicians involved with their transition, 83% indicated that they had been told of the differences between paediatric and adult AH services, 66% knew where the adult AH services were, 83% knew when transition would occur. However, 66% had not been given any information about what services they would transition to.
- The key areas in which client and consumers wanted information to assist with transition were; differences between adult and paediatric Allied Health services, what is transition

and when does it occur, financial and medical decision-making, Centrelink and government entitlements, and a young person's role and responsibilities during transition.

ii. **Client and Carer Interview**

- 27 phone interviews attempted
- 5 successfully completed

These key findings were gathered from interviews:

- Majority of participants identified transition as moving from adult to paediatric services.
- Clients identified the increasing independence associated with transition "I will be dealing with the doctors myself".
- Carers reported main concerns as accessing services adult Allied Health services and having consistent contact with a therapist.
- Clients and carers currently preparing to transition felt they had not been provided with adequate information on transition.
- Majority of participants were unable to identify how to access adult Allied Health services.
- Limited knowledge of services offered by Allied Health.
- Majority of participants felt confident in accessing education and vocational services.
- Discrepancy between information provided on transition (as per file audit) and what clients were reporting which reinforces the importance of beginning the transition process early.

iii. **Clinician Interview**

- Direct meetings with relevant AH Heads of Discipline at JHCH

These key findings were gathered from the interviews:

- No formal transition pathway for AH clinicians working with this population.
- Minimal awareness of current AH adult services available for this population.
- Paediatric clinicians frustrated with the lack of clear adult services for this client group which leads to clinicians "holding" onto these clients after they have become adults in an attempt to continue providing family-focused care.
- Paediatric clinicians feel like they are "talking" up adult services that in reality don't exist for this population.
- No paediatric/youth rehabilitation specialist to provide case management throughout transition and early adulthood.
- Paediatric clinicians forced to adopt a "transfer" model rather than a "transition" model, as there are no adult services coming forward to bridge the gap between existing paediatric services.
- Concerned that GPs are being asked to be case managers for this population with minimal information on the AH service needs of this population.
- Concerned that clients are disillusioned with the health system as they realise that the current adult services are not appropriate for their needs; thus increasing the risk of them not accessing services for regular reviews which may prevent the development of serious medical problems and the need for hospital admissions.
- Concerned about the population with cognitive and developmental delays, which places them at a higher risk of not accessing appropriate services, as they are unable to advocate for themselves.
- Concerns surrounding the palliative care population and how they are managed with respect to their age and social needs.
- No counselling or support services for this population to assist with working through transition.
- Current resources available require a high level of literacy, which the clients and carers do not often have. Also whilst there is a lot of information on the Internet, the assumption should not be made that the clients have access to the Internet at home.
- No consistency with transitioning between different specialists, which creates service confusion for clinicians managing these clients, especially when clients who have been transitioned in the community are readmitted to the JHCH, even though they are adults.

iv. **Clinician Questionnaire**

- Paediatric and Adult specific questionnaires were sent to all clinicians working in the Newcastle area.
- 8 paediatric clinician questionnaires returned
- 1 adult clinician questionnaire returned

The key findings from the survey were:

- Majority of clinicians have a good understanding of the core principles of transition and the role of the GMCT Transition service.
- Lack of appropriate adult AH services for paediatric clinicians to transition clients with complex disabilities to.
- Reluctance to transition complex clients due to the above. In some cases clinicians did not transition clients and continue to provide intervention to young adults due to lack of services available.
- Nil concerns raised regarding transition within diagnostic groups which have clear formalised transition pathways i.e. Diabetes, Cystic Fibrosis
- Lack of formal transition guidelines in the Greater Newcastle Area.
- Lack of resources available to Adult clinicians to assist transition.
- Difficulty transitioning clients in diagnostic groups who do not have an organised team and therefore designated team leader.
- General consensus that the bulk of the work in ensuring a smooth transition for clients falls upon paediatric clinicians.

v. **JHH and RNC Allied Health Outpatient Services Data**

- AHMIS data was analysed from JHH and RNC for each Allied Health discipline for young persons aged between 16-24 from 2002-June 2007.
- AHMIS data was analysed from JHH and RNC for each Allied Health discipline for persons aged over 24 from 2002-June 2007.
- Total number of patients referred to each discipline was determined over the 5-year period. Data graphs by discipline, site and year are available in Appendix 3.

The key findings from analysis of the data were:

- Numbers of young adults aged between 16-24 accessing adult outpatient services is increasing across all disciplines over the last 5 years.
- Most noticeable increases were in Nutrition and Dietetics, Social Work and Occupational Therapy.
- Nutrition and Dietetics recorded 261% in outpatient numbers to June 2007.
- Social Work recorded a 950% increase to 2006 (which excludes Obstetrics and Gynaecological services)
- Occupational Therapy services demonstrated a 690% in outpatient numbers since 2002.
- In the 6 months until June this year, Nutrition and Dietetics and Occupational Therapy had seen 87% and 92% of the outpatient numbers from the entire year of 2006 respectively.
- Number of adults aged over 24 accessing outpatient services at JHH/RNC has increased for all disciplines over the last 5 years.
- Significant increases were noted in Physiotherapy and Speech Pathology with a 115% in numbers over the last 5 years.
- A 125% increase noted for Nutrition and Dietetics and Occupational Therapy.
- Social Work recorded a 150% in outpatient numbers to June 2007.

vi. **File Audit**

- 30 files were selected from the mail-out list generated from JHCH AHMIS data. Files were excluded with a date of birth after 1990, as they were not considered to be at transition age for the purposes of the file audit. Files were also excluded if minimal Allied Health intervention was noted and therefore transition was not required. Acute medical conditions were excluded e.g. fractures and MVA's without evidence of chronic disability. A number of files were unavailable at the time of the audit.
- A total of 7 suitable files were reviewed and information was collected regarding paediatric and adult Allied Health intervention, documentation regarding transition, timing of transition and information sharing between clinicians. Principal diagnoses included Cystic Fibrosis, Cerebral Palsy, Muscular Dystrophy and Diabetes.

The key findings from the file audit were:

- Coordination of transition was poor for clients involved with multiple medical specialities. For example 1 client was transitioned to adult Neurology services 7 months prior to being transitioned to adult Respiratory services.
- Complex clients predominantly with degenerative conditions were not transitioned to adult services. For example 1 client continued under the care of Paediatric medical and Allied Health services at age 20. Likely reflects paediatric clinicians concerns regarding the lack of appropriate Allied Health services to transition these clients to.
- Large number of clients reconnecting with adult Allied Health services on admission to hospital. Some clients had not received Allied Health intervention for 3-4 years on admission.
- Inpatient Allied Health services often referred clients back to services in the community. Difficult therefore to determine if appropriate Allied Health intervention was maintained after discharge.
- Diagnostic groups such as Cystic Fibrosis, Diabetes and Spina Bifida were as expected, transitioned with no gaps or disruption in service provision detected. Direct communication between Medical Officers and Allied Health clinicians evident in file.
- Medical specialists often requested or 'strongly recommended' clients access adult services. Minimal assistance provided other than referral letter and contact details. 1 client failed to transition to appropriate adult medical services when this approach was adopted.
- 1 example of 'planned and coordinated approach' to transition evident. Documented discussions regarding transition between client and Medical officer. Transition coordinator directly involved.

d. Findings/Outcomes with Respect to Project Objectives

Objective	Findings / Outcomes	Source
<ul style="list-style-type: none"> ▪ Gain a clear picture of the young people attending the JHCH Allied Health services <ul style="list-style-type: none"> ○ Condition ○ Ages ○ Therapy received and ongoing needs 	<ul style="list-style-type: none"> ▪ 172 young people with chronic conditions are transitioning per year from paediatric services at JHCH at age 18-20 years. <ul style="list-style-type: none"> ○ 70 Neurology ○ 38 Endocrine ○ 9 Gastroenterology ○ 2.5 Asthma ○ 12 Adult Diseases ○ 5 Spina Bifida ○ 3.5 Cystic Fibrosis ○ 2 Brain Injury ○ 30 Diabetes ▪ All of these clients would be accessing AH services at the JHCH. AHMIS data was not able to provide a clear picture as to how many clients with chronic conditions were accessing specific AH disciplines. ▪ At discharge from the JHCH AH services all of the above clients would require some form of ongoing AH therapy such as: <ul style="list-style-type: none"> ○ Ongoing reviews (2-3 per year) ○ Ongoing therapy sessions to achieve specific goals eg: seating, diet related, limb management, post surgery care. 	<ul style="list-style-type: none"> ▪ HNEAHS Transition Care Clusters Document ▪ AHMIS data from 2006-2007 of clients accessing AH OP services at JHCH and JHH
<ul style="list-style-type: none"> ▪ Research what resources (within health and the community) are currently available to young people who require ongoing Allied Health intervention after they leave paediatrics. 	<ul style="list-style-type: none"> ▪ Adult AH services (primarily consultative) can be accessed through Royal Newcastle Centre and Community Health Centres in the Newcastle area, some may need GP referrals. ▪ Non-Government Organisations that could provide appropriate services for the client group were identified and their information collated for clinicians to distribute appropriately to clients. 	<ul style="list-style-type: none"> ▪ AH adult services in Newcastle area document. ▪ Non-Government Organisations in Newcastle area.
<ul style="list-style-type: none"> ▪ Obtain consumer input <ul style="list-style-type: none"> ○ Talk with young people and their parents/carers about their needs during transition ○ Compile their stories 	<ul style="list-style-type: none"> ▪ Clients and clinicians do not currently have enough information or support structures (such as: staffing levels, appropriate services to refer to and liaise with, consistency in service provision across paediatric medical teams) to implement a planned approach to transition at the JHCH. ▪ Clinician's do not have enough clinical time to implement a planned approach to transition for their clients. ▪ Clinician's do not have enough education on the process of planning transition to feel comfortable implementing the process. ▪ Medical support is generally not present for transitioning. ▪ Adult clinician's often do not have the necessary skills to manage this complex population that requires ongoing, developmentally appropriate care. ▪ Adult clinician's generally do not have the time to manage this complex population. ▪ Clients and carers are significantly unprepared and unaware of the differences between paediatric and adult Allied Health services. ▪ Clients and carers are consistently unhappy with transfer to adult services, especially the lack of family- 	<ul style="list-style-type: none"> ▪ Consumer mail out conducted to 300 clients of HNEAHS accessing AH services at JHCH in past 12 months between ages of 14 – 21 years with chronic condition/illness. (20 appropriate questionnaires returned). ▪ Consumer interview of clients accessing AH services at JHCH approaching discharge age. (5 appropriate interviews conducted). ▪ AH clinician interviews conducted at JHCH (5 interviews conducted with Heads of Discipline). ▪ AH clinician surveys gathered from paediatric and adult AH services in Newcastle area. (1 Adult survey returned, 8 Paediatric surveys returned).

Objective	Findings / Outcomes	Source
	<p>based therapy approaches.</p> <ul style="list-style-type: none"> ▪ Clients and carers consistently requested that adult services be like child-based services. ▪ Clients and carers had limited knowledge of what each Allied Health professional did, which professional to go to for assistance and what adult Allied Health services were available. They were consistently confused by terminology which used "Allied Health Professionals" to describe these disciplines. 	
<ul style="list-style-type: none"> ▪ Identify gaps that exist in service provision for young people that require transitioning to adult Allied Health services. 	<ul style="list-style-type: none"> ▪ Gap in provision of developmentally appropriate AH services in Newcastle area for population of young people with chronic conditions/illnesses. Limited services to transition clients to and therefore on occasions transition is not occurring. ▪ High need to implement an AH service model that is developed with respect to clientele's developmental, cognitive, social and lifestyle needs to boost young people accessing services prior to developing illnesses / exacerbating illnesses and requiring hospitalisation. ▪ Increasing numbers of young adults accessing Adult AH outpatient services. Significant increase in remainder of adult population also accessing these services with minimal staffing enhancement to cope. 	<ul style="list-style-type: none"> ▪ Clinician interviews and surveys. ▪ Consumer questionnaires and interviews. ▪ AHMIS data from 2002-2007 of clients accessing AH OP services at JHH and RNC. ▪ File Audit
<ul style="list-style-type: none"> ▪ Work with consumers, paediatric and adult clinicians to develop a transition process for young people attending Allied Health services at JHCH, including recommendations to reduce ongoing gaps in service provision. 	<ul style="list-style-type: none"> ▪ Developed transition guidelines for AH services at JHCH to assist clinicians manage complex population. Guidelines are in line with standard recommendations from GMCT – Transition Care. ▪ Guidelines were preferable to developing a structured transition plan as the population is heterogeneous and need differing support and guidance from clinicians. ▪ Primary focus of the guidelines is to up-skill paediatric clinicians, increase awareness of transition needs for this population and assist clinicians focus on developing specific client skills which will be assistive to the client when accessing existing adult AH services. ▪ Guidelines recommend paediatric clinicians increase the amount of information exchange with existing adult AH services in an attempt to reduce the time lag between services, reduce the need for the client to continue to reiterate their developmental and therapeutic history and increase the client's confidence in accessing adult services. ▪ Recommended paediatric and adult services investigate the potential funding to implement a young person's clinic at JHH to provide developmentally appropriate ongoing therapeutic care for this population. This would be the most effective way to manage the existing gap in appropriate AH services for this expanding population. 	<ul style="list-style-type: none"> ▪ Information gathered from clinician and consumer surveys and interviews used. ▪ Liaised with AH paediatric services for feedback on development of guidelines. ▪ Young Adults Transition Service, Monash Medical Centre, Melbourne. ▪ Spina Bifida Service, The Royal Melbourne Hospital, Melbourne. ▪ Literature review

The consumer surveys indicated that there is a general lack of Allied Health services in the GNS area for young people with a chronic condition. Young people and their carer's in the area are confused about the sudden transfer to adult services and feel that they do not have the necessary skills to navigate adult Allied Health services. They also do not describe or indicate familiarity with the transition process as recommended by GMCT – Transition Care.

Consumer's also indicated that they wished that existing adult services were similar to paediatric services, which is not surprising considering the paediatric system favours a family-centred approach as opposed to the client-centred approach of the adult health system. Further consideration of this statement however indicates that consumer's are not aware of the need to develop the independent self-help skills of clients to allow them to access and navigate adult services. It also suggests that consumer's are not familiar with the concept that continuing to manage these clients in the paediatric system, as they become adults is inappropriate.

The majority of clinician feedback indicates that those working in the area of transition are familiar with the recommended process but do not have access to resources to support implementation of transition as recommended by GMCT and current literature. Clinician's identified a lack of developmentally appropriate services for young people when discharged from paediatric AH services. They felt that the adult services expected "too much" from clients that are still developing skills such as independence, problem solving, insight and self-awareness.

The above findings are consistent with the results from the literature review, which incorporated findings from the UK and USA with regard to parental views and client views towards services and transition processes.

e. Resources Developed

The following resources were developed for the AH professionals at the JHCH to assist with implementing a transition process for this population in the present service environment. From the clinician surveys, it was identified that the current AH professionals working at JHCH have a reasonable understanding of the transition process but admit to limited access to transition care resources and high workloads which creates barriers to achieving successful transition. These resources were developed to assist clinicians further develop their skills in the area of transition care.

- i. Transition Guidelines for Allied Health disciplines in GNS. (Appendix 6)
- ii. Allied Health service mapping for adult AH services in the Hunter to assist with appropriate referral and information provision to consumers – ongoing into 2008. (Appendix 9)
- iii. List of appropriate Non-Government Organisation's in the Newcastle area for clinicians to refer young people to for assistance with life skills, vocational issues/endeavours, education and training options. (Appendix 7)
- iv. Implementation of a short cut from HNEAHS intranet site to GMCT Transition Care website to assist with clinicians accessing existing Transition Care resources for professionals and consumers (Appendix 4)

6. Recommendations

a. Short term

i. Transition Procedures for Allied Health

The AH guidelines for transition were developed from existing GMCT Transition resources and the Interim Transition Guidelines Policy for HNEAHS, Kaleidoscope Children's Services. Consultation with existing AH professionals in JHCH, the Transition Co-ordinators for HNEAHS and for GMCT was conducted.

The guidelines are attached in Appendix 6.

- It is recommended that AH disciplines use the guidelines and the HNEAHS policy to develop their own discipline specific transition processes that link with existing processes in disease specific services in JHCH: such as Neurology, Spina Bifida, Cystic Fibrosis and Diabetes.
- Encourage clinicians to provide information that is appropriate to education and literacy level of clients. Transition information sheets are available on the GMCT website and can be easily modified to meet the needs of individual clients and their carers.

ii. Increased funding for Allied Health.

Increase funding and support to all AH disciplines providing OP services to enable them to manage this growing population and implement effective transition pathways as per GMCT standards. The data obtained indicates that the 16-24 age group is placing increasing demands on Allied Health adult resources in the Hunter. The data also demonstrates a concurrent rise in demand from an ageing population over the last 5 years. Considering this, it is reasonable to assume that the time available to all consumers is limited due to staffing. This is concerning when you consider the complex and long term nature of the intervention required for the adolescent age group making the transition to adult services.

iii. Support for Project Participation

Obtain further support from management level to assist and encourage clinicians to participate in future projects. One of the confounding factors throughout this project was the lack of readily available information on clinician needs. This project has identified multiple projects aimed at improving the transition experience for young adults. It is recognised that strong collaborative input from both adult and paediatric services is needed for these to be successful and promote change within HNE Health.

iv. Flagging and Tracking

Develop a more appropriate tracking system for children with chronic conditions to enable future projects to collate accurate statistics on frequency and range of services accessed including emergency and inpatient admissions.

v. Involve General practitioners in the Transition Process.

Liaise with GP services to assist them become more involved with the transition process and aware of the ongoing medical and health needs of the client. This would assist them in improving case management skills for young people with chronic conditions.

vi. Information Sharing

Development of an Allied Health Transition Care Forum to meet regularly throughout the year (approx 4 times) to focus on case transitioning needs, education of clinician's on the management of adolescent and young persons population (managed by Transition Care Co-ordinator in the area).

Transition Care Co-ordinator to present topics and updates on transition issues at the annual discipline specific education forums to improve paediatric and adult clinician's awareness and interest in the area of transition care.

Develop education sessions for clients and carers to attend to assist them to plan and be active in the transition process. Education should focus on:

- Ways to communicate with AH professionals and medical staff about transition.
- How to plan for transition.
- When to start the transition process.
- What are the differences between child and adult services and how can I manage adult services.
- Increasing independence in your adolescent with a chronic condition.
- Financial and educational considerations.

This would be best implemented as a team project with all Allied Health disciplines involved with the formulation and application.

b. Long Term

i. Establishing a Young Adult's Multi-disciplinary Clinic

Implementation of a young person's clinic with Allied Health professionals specialising in the management of young people with regard to developmental and psychosocial issues, cultural and lifestyle factors would be ideal in terms. The clinic would include PT, OT, Dietetic, SW and SP services and medical consultation by a young persons rehabilitation specialist. Current statistical records of client numbers indicate that there is a significant emerging population in the Newcastle area in need of access to such a specialised clinic. This would reduce the increasing burden on both community and hospital OP AH services. It would also reduce the number of young people failing to make the transition from paediatric to adult services due to lack of awareness or information on available services.

Young Adult Disability Clinics have been implemented in Victoria at such institutions as Monash Medical Centre, Royal Melbourne Hospital and St Vincent's Hospital. These clinics provide developmentally appropriate consultative AH services to young people with chronic conditions.

The clinics are designed to:

- Provide services for young adults with chronic and complex medical conditions.
- Developmentally sensitive and appropriate intervention for the population.
- Incorporate a model of care that enables the consumer to navigate a health care model similar to adult services as opposed to paediatric services.
- Provide medical rehabilitation specialist service and referral to appropriate adult consultant specialists when needed.
- Provide the range of Allied Health services for this population's needs; including occupational therapy, physiotherapy, social work, speech pathology and dietetics.
- Provide multidisciplinary input and case management within a single setting thus reducing client and carer travel and stress and greatly improving continuity of services.

It is recommended that the JHCH and JHH AH services collaborate to systematically review existing clinics in order to determine the best possible design for implementation in Newcastle. Information specific to the clinics operating within Victorian Health including current staffing levels and statistics is available in Appendix 8.

7. Conclusions

Currently in GNS there is minimal transition of young people with chronic conditions, where transition refers to the “purposeful, planned and organised movement from paediatric services to adult services”. Instead the information gathered indicates that the current trend in Allied Health services is to transfer a client to an existing adult service for their specific condition (i.e., diabetes) or to hold onto them in the paediatric system until they are deemed “stable” and then discharge them with some information on how to access further adult AH services in the area. It has also been indicated that the system of transferring clients from paediatric to adult services is confounded by medical consultants “holding” onto these clients into adulthood, and continuing to admit them into the Children’s Hospital and refer them to paediatric AH services. This process is further confused when multiple medical specialities are involved which is often the case, and transition to adult services is occurring at differing times depending on the consultant involved.

It is clear that the current situation is not compliant with recommended transition process from GMCT – Transition Care, NSW Health. Nor is the current situation reflecting recognised standard practises with regard to transition from the UK, USA or Victorian Health. It is also clear that while there are transition plans in place for some specific chronic conditions (eg, head injury, diabetes and cystic fibrosis) there are minimal documented procedures or recommendations in HNEAHS to assist AH clinicians to develop and implement transition plans for clients that belong to the heterogeneous group of chronic conditions which makes up the bulk of the AH JHCH OP caseload; such as neurological conditions, spina bifida, neurodegenerative conditions, neuromuscular conditions and palliative care cases.

The findings indicate that the management of transition for young people with chronic conditions from paediatric to adult AH services are generally limited in the Newcastle area. The findings also indicate that clients, carers and clinicians are keen to see improvements in this area of service provision, however feel that there is a lack of resources, support and information available to do so. In terms of lack of resources for clinicians, the transition guidelines (Appendix 6) have been completed to support clinicians with the process of transition. In addition to this it is recommended that the education process for transition continue in the Newcastle area with the assistance of the GMCT Transition Care Co-ordinator. It is felt that this education process needs to be extended also to GP’s who act as primary health care providers for this population and therefore possibly could play a pivotal role as case manager in transition.

The priority gap in service provision, as identified by this project, is the shortage of developmentally appropriate and specialised adult Allied Health services for young adults with chronic conditions to transition to upon leaving paediatric services. The need to implement an AH service model which reflects the complex needs (developmental, social, cognitive, physical, medical) of this population is paramount to ensure continuity of service and improved quality of life for these young adults. Results from this project demonstrate that transition pathways are successful when a specific diagnostic group has established paediatric and adult multidisciplinary clinics to promote strong continuity of service such as in Cystic Fibrosis, Diabetes and Head Injury. The transition guidelines as discussed above are currently generic in nature to accommodate the heterogeneous nature of the remaining population. The establishment of a young person’s complex disability clinic similar to successful clinics currently operating within Victorian Health would enable a more formal and standardised transition pathway to be implemented for this population. It would also address the identified gap in service provision by providing access to multidisciplinary specialised rehabilitation input and case management upon leaving paediatrics. It is the recommendation of this project that further investigation commence into the feasibility of creating such a specialised clinic in Newcastle ideally located at JHH or RNC.

In summary, the population of young people with chronic conditions being discharged from JHCH OP AH services is increasing each year. This population requires consistent ongoing, developmentally appropriate AH therapy services in the Newcastle area. OP services that are developmentally appropriate are more likely to be accessed by this population, rather than the existing adult AH OP services. Ideally as supported by literature and current trends in service provision the establishment of a Young Adults Complex Disability would address existing gaps in service provision and provide the necessary therapeutic intervention to this complex and ever-expanding population. Supporting this population to access AH OP services will assist in improving their health and lifestyle, motivation towards health care, self-help skills and ultimately reduce the number of emergency hospital admissions for management of acute problems that may have been avoided if regular OP therapeutic AH services were made available.

8. Future Directions

Future Areas of Investigation:

- i. The need for a specific clinic for young adults with complex disabilities has already been established above. There is a strong need to systematically review current clinics in operation to determine a suitable clinic design to meet the needs of young people in the Newcastle area. It is proposed that this project would require a strong collaborative approach from both paediatric and adult Allied Health services to ensure the clinic meets the needs of the transitioning population and relieves the burden on limited adult AH services. The literature review completed within this project provides key ingredients for successful transition processes and theoretical frameworks for models of transition. The next step is to tailor a suitable clinic model to meet the specific needs of adolescents with complex disabilities in the Hunter.
- ii. Investigate the role of the General Practitioner as case manager for young people with chronic conditions in the community.
 - o Are GP's interested in this role?
 - o What understanding do GPs have regarding transition for this population?
 - o What information and support do GP's need to help them manage this population in the community?
- iii. Flagging clients with chronic and complex disability conditions in the health system would enable them to be tracked through the paediatric and adult out patient and inpatient services. The outcome would be more accurate data regarding client numbers, hospital admissions and estimated costs to the health service. This would create a pool of data, which would provide more information on transition for future projects (as listed above) and support the case for increased funding for Allied Health.

APPENDIX 1 – LITERATURE REVIEW

Citation	Level of Evidence / Style of study	Area of Study	Findings in Relation to Project
<p>1. Shaw, K.L., Southward, T.R., and McDonagh, J.E. (2004). Transition care for adolescents with juvenile idiopathic arthritis: a Delphi study. <i>Rheumatology</i>, 43; 1000-1006.</p>	Questionnaire	<p>Shaw, Southward and McDonagh (2004) reported on the “transition care for adolescents with juvenile idiopathic arthritis” (JIA). This involved investigating the views of Allied Health professionals, consultant and consumers on what constitutes best practise in managing transition from paediatric services to adult services.</p>	<p>Their investigation indicates that the following were identified as being best practice and highly feasible to be implemented in hospitals and community services:</p> <ul style="list-style-type: none"> ▪ Addressing psychosocial and educational / vocational needs; ▪ Offering individualised approach; ▪ Providing accurate and honest information to client and carer; ▪ Providing an atmosphere which encourages an adolescent to voice their thoughts, opinions and make informed decisions; ▪ Continuity of care; and, ▪ Providing the opportunity for the adolescent to see the professional alone. <p>These areas were identified as needing development in their current services:</p> <ul style="list-style-type: none"> ▪ Multidisciplinary Teams. ▪ Professionals knowledgeable in adolescent development. ▪ Adolescent appropriate environments. ▪ Opportunities to meet similar others. <p>In particular Allied Health professionals were to agree that the following constitute best practise:</p> <ul style="list-style-type: none"> ▪ Honest explanation of adolescent’s condition and health care needs. ▪ Addressing Psychosocial and educational /vocational needs is as important as addressing medical needs. ▪ Multidisciplinary teams are essential to the best care of adolescents with JIA. ▪ Continuity in health personnel is essential in building adolescents’ trust, confidence and willingness to disclose. ▪ Facilitating self-advocacy skills (eg, decision-making, effective communication, disclosure). ▪ Close co-operation between paediatric and adult services. ▪ Strong interagency links are essential for transition care.
<p>2. McDonagh, J.E., Southward, T.R and Shaw, K.L. (2004). Unmet education and training needs of rheumatology health professionals in adolescent health and transition care. <i>Rheumatology</i>, 43: 737-743.</p>	Questionnaire	<p>McDonagh, Southward and Shaw (2004) investigated the perceived education needs of health professionals working with JIA requiring transition. The clinical bottom line reported was that “Rheumatology health professionals have unmet education and training needs in adolescent health and transition care”.</p>	<p>The following specific areas of training were identified as being important and unmet:</p> <ul style="list-style-type: none"> ▪ Transition issues (models/frameworks, existing programmes, intra-and-inter-agency coordination, planning). ▪ Resources ▪ Interagency services ▪ Vocational issues ▪ Benefit entitlement and legislative issues ▪ Psychosocial issues (adolescent development, mental health, social support, peer issues) ▪ Generic and sexual health issues

<p>3. Fleming, E., Carter, B. & Gillibrand, W. (2002). The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. <i>Journal of Clinical Nursing</i>, 11: 560-567.</p>	<p>Literature Review</p>	<p>Fleming, Carter and Gillibrand (2002) reviewed literature concerning transition of adolescents with diabetes from children's health care into adult health care service.</p>	<p>They documented the following trends.</p> <ul style="list-style-type: none"> ▪ Advances in medical science mean that most children with diabetes will survive to adulthood. ▪ The transition period has the potential to cause instability in the adolescent's already vulnerable position, and so it is the place of the health care team to ensure that the transition process is a positive experience for the adolescent, which builds and developed the person empowering them to become a well-balances, independent individual.
<p>4. Luther, B. (2001). Age-Specific Activities that Support Successful Transition to Adulthood for Children with Disabilities. <i>Orthopaedic Nursing</i>, 20(1); 23-29.</p>	<p>Questionnaire and Focus Groups. Level III - 3</p>	<p>Luther (2001) reported on the activities that might best support adolescents transitioning to adulthood through a focus group of parents of successful young adults with disabilities. The aims were to provide health professionals with an insight into the activities that foster a child's independence throughout development.</p> <p>The purpose of the study was to evaluate the following recommendations made by Blomquist, et al (1998) by parents who had been successful in transitioning their children with disabilities into adulthood.</p>	<p>The following comments were made regarding health professionals needs when managing this population:</p> <ul style="list-style-type: none"> ▪ Understanding that the needs of this population go beyond basic health care and disease management to include teaching on the issues of transition to adulthood. ▪ Knowledge about the domains of long-term planning for the client's health, education, independent living and employment in adulthood. ▪ Including teaching developmental activities that promote the skills of independence, self-care and self-determination. ▪ Failure to address the issues of self-care, education, employment and independence sends a subtle message that these issues are not important, the child will not be able to care for himself / herself and the child will not be able to make the transition to adulthood and adult care providers. <p>The parents were asked to rate level of agreement using a 5-point Likert Scale (1 = strongly agree, 5 = strongly disagree). 77% of the activities had an agreement rating between 1-1.5.</p> <ul style="list-style-type: none"> ▪ Do not do for them what they can do for themselves ▪ Assign appropriate household chores ▪ Help interact with others in various settings ▪ Help the children talk to health care providers to aid the child in taking responsibility for their own health care ▪ Talk to children about their interests and abilities and how their levels of abilities affect their career choices ▪ Help adolescents to focus on talents, likes, personality traits, supports challenges to develop self-awareness as they look toward their future ▪ Help young teens find small-paying or volunteer jobs ▪ Get written information about the teen's state vocational rehabilitation program and school-based transition program ▪ Make a transition plan for adult living, including health services ▪ Find out about school's individual education program ▪ Help teen and family develop independence in care for self, taking medications, teamwork and expressing confidence ▪ Young person should learn about disclosing information and advocating for his/her needs ▪ Ask about adult plans and what will make these plans happen ▪ Young person should know about body changes and how the disability will affect future health, vocational choices, marriage and children ▪ Young adult should apply for Medicare card and government benefits at age 18 if appropriate ▪ Assist the adolescent in finding an adult healthcare provider ▪ Assist the adolescent in understanding financial issues <p>Health care professionals play a vital role in developing a child's ability to talk to them. Parents suggested talking directly to the child, listening and encouraging them to learn about their diagnosis and how it affects them.</p>

<p>5. Sawyer, S.M., Blair, S. & Bowles, G. (1997). Chronic illness in adolescents: Transfer or transition to adult services? <i>Journal of Paediatrics and Child Health</i>, 33(2): 88-90.</p>	<p>Review</p>	<p>Review of the need for transition, transition processes and development / modification of adult services to manage increasing population of young people with chronic illnesses.</p>	<p>Key Points:</p> <ul style="list-style-type: none"> ▪ The technological and therapeutic advances of modern paediatric care have resulted in a new generation of adolescents surviving with chronic illness and disability. ▪ Endorses the concept that continuity of developmentally appropriate care ideally is provided for young adults with chronic illness in adult-based facilities. ▪ Transition is an integral component of child and adolescent health. <p>Barriers for Transition:</p> <ul style="list-style-type: none"> ▪ Young person may have strong feelings of abandonment at being transferred from a health professional that they have had long-term association with. ▪ The “individual” approach taken by adult practitioners can be threatening when compared to the “family” approach of paediatric services and cause anxiety in the client and carers. ▪ Paediatricians being reluctant to transfer clients to adult services due to lack of familiarity with the disease process. Unfortunately, this can lead to a “crisis” being the reason for a transfer – eg, attempted suicide, unexpected pregnancy or hospital admission policy regarding “overage” patients. ▪ Time limitations. ▪ Health professional's failure to provide carers and client with necessary information to make a successful transition as apposed to a transfer. This lack of education sets the clients and carers up for failure in the adult system. <p>Models of Transition:</p> <ul style="list-style-type: none"> ▪ Disease focussed – transferring from a paediatrician sub specialist to another sub specialist. ▪ Primary care-based – co-ordinated by the GP. However, lack of integration with specialist care, time required and lack of communication skills when interacting with adolescents are factors that may limit the practicality of this model in Australia. ▪ Generic adolescent health services – with adolescent medicine specialist's co-ordinating care. <p>Principles for Transition:</p> <ul style="list-style-type: none"> ▪ Planned co-ordinated approach. Anticipation of physical transfer from the time of diagnosis is one way of ensuring that the physical move is truly part of a transition process. ▪ An adult physician or team that is both interested and capable of providing care is fundamental. ▪ Compilation of a detailed medical and Allied Health summary is important for the new team, as are regular meetings between the paediatric and adult providers. ▪ Explicit expression of trust for the adult team by the paediatric team will also help build patient confidence. ▪ Timing the physical move may vary, it should be individualised according to other important transitions. (e.g., school transition), psychological and cognitive maturity of the young person and the severity and stability of the disease. ▪ Transfer at a time of disease stability. ▪ During adolescence, young people should be increasingly responsible for their health, with family urged to accept their new role as supporters and advocates with less direct responsibility for health. ▪ Personal introduction to the new physician and team will reduce the anxiety of the unknown and a visit to the new centre prior to transfer will hopefully render it less frightening. ▪ Provide adequate opportunities to discuss the move with both the young person and their parents will help alleviate feelings of abandonment and allow the transfer to be framed in a more positive way by all parties.
<p>6. Callahan, S.T., Feinstein Winitzer, R., & Keenan, P. (2001). Transition from paediatric to adult-oriented health care: a challenge for patients</p>	<p>Questionnaire</p>	<p>The paper distinguishes medical transition from medical transfer, discusses potential barriers to transition, examines new initiatives to develop and study transition models and reviews federal legislation influencing health care transitions.</p>	<p>Transition vs. transfer:</p> <p>Transition is an anticipated, co-ordinated process; eg “ the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems” (Blum et al, 1993). Transfer is an event, only one component of medical transition.</p> <p>Barriers to Transition:</p>

<p>with chronic disease. <i>Current Opinion in Pediatrics</i>, 13; 310-316.</p>			<ul style="list-style-type: none"> ▪ Paediatric Provider <ul style="list-style-type: none"> ○ Long-standing relationships can make transitioning difficult. ○ Provider may have the opinion that their skills are adequate or preferable for the care of the chronic condition regardless of the patient's age. ○ Provider may be unfamiliar with community resources or lack the time or knowledge to effectively coordinate the transition process. ○ Family have limited contact with a GP as they view the specialist to be the "main" physician. ▪ Adult Provider <ul style="list-style-type: none"> ○ Lack of providers willing to care for the young adult with a chronic disease. ○ Adult providers have little training in the management of disease that have traditionally been seen as being childhood maladies. ○ Lack of care commitment from hospital or clinic to support physician. ▪ Patient and Family <ul style="list-style-type: none"> ○ If the transition process is not well coordinated and/or occurs at a time of crisis it can be perceived as abandonment. ○ Understanding and managing the differences between paediatric and adult services can be challenging and intimidating. ○ While paediatric services rely in input from the family, adult services functioning through direct interaction with the client only. <p>Timing of Transition: Chronological age is an insufficient guide to transition only. Providers need to encourage and facilitate a planned well-organised transition process. It is the health provider's responsibility to educate the client about his/her condition and foster independence in manage the condition as well as self-care skills. Increasing the client's independence will increase their ability to successfully transition to an adult provider.</p> <p>During early adolescence the client and his/her team should develop a schedule for transitioning. The client should be given and active role in determining the timing of these events.</p> <p>Checklist for Evaluating Readiness:</p> <ol style="list-style-type: none"> 1. I know my height, weight, birth date and social security number. 2. I know the name of my condition, can explain my special health care needs and can tell about my health status. 3. I know whom to call in the case of an emergency. 4. I ask questions during my medical appointments. 5. I respond to questions from my health care providers. 6. I know what kind of medical insurance I have. 7. I know the names of my medications and what they do. 8. I know how to get my prescriptions refilled. 9. I know where to find my medical records. 10. I have discussed the use of tobacco, alcohol and drugs with my provider. 11. I have discussed my sexuality issues with my provider. 12. I know how to get birth control and protection from sexually transmitted diseases. 13. I know how to schedule an appointment. 14. I keep a schedule of my medical appointments on a calendar. 15. I can get myself to my medical appointments.
<p>7. Blum, R.W. (1995).</p>	<p>Review</p>	<p>Comment on previous transition focussed conference and current</p>	<p>There are still many people in the United States who will argue that you should not transition young adults with special needs, that a pediatrician should follow these young people throughout adulthood. The reasons why this perspective is intolerable</p>

<p>Transition to Adult Health Care: Setting the Stage. <i>Journal of Adolescent Health</i>, 17; 3-5.</p>		<p>situation. Introduction to new conference.</p>	<p>are many: adult maturation requires each of us to be treated as an adult; infantilisation delays maturation; adult expectations promote both independence and personal responsibility; and it promotes improved health outcomes.</p>
<p>8. Blum, R.W., Garell, D., Hodgman, C.H., Jorissen, T.W., Okinow, N.A., Orr, D.P. & Slap, G.B. (1993). Transition from Child-centred to Adult Health-Care systems for Adolescents with Chronic Conditions. <i>Journal of Adolescent Health</i>, 14; 570-576.</p>	<p>Review, questionnaire</p>	<p>The purpose of this paper is to address transition issues of people with chronic illness or disability. Where the optimal goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive.</p> <p>Transition is defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems.”</p> <p>To further that definition:</p> <p>“A multifaceted, active process that attends to the medical, psychosocial, and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health care system. Health transition facilitates transition in other areas of life as well (eg, work, community, and school). It implies an increase in independent behaviour and personal autonomy but need not entail a change in health providers... in other words, transition is <i>more</i> than, and sometimes distinct from, simple referral to a physician caring for adults.” p 573.</p>	<p>Key points:</p> <ol style="list-style-type: none"> 1. More than 85% of children with chronic conditions survive to adulthood. 2. High rates of survival mean that there are increasing numbers of adolescents confronted with the issues and barriers in transitioning from child-centred care to adult-oriented care. 3. The shift in services from institutional to community-based and family-centred care has increase public recognition and the importance of transition. 4. Due to increase in medical care and science the rates of young people with chronic illness will increase. Thus, the future health status for this increasing population needs a health care foundation that is medically excellent and psycho-socially sound. 5. Smooth transition should be a priority and shared responsibility of paediatric and adult health care providers. 6. All adolescents when developmentally ready should receive their health care through adult-oriented services. 7. All adolescents should be given the opportunity to transition in a planned and purposeful way. <p>Key Elements to Successful Transition:</p> <ol style="list-style-type: none"> 1. Professional and environmental support 2. Decision-making and consent 3. Family support 4. Professional sensitivity to the psychosocial issues of disability. <p>What occurs when a transition plan is not in place is a dramatic and forceful transfer into a system that has not been prepared for the client and a client that feels pushed out of a supportive environment into a perceived unsupportive and alien care setting. Thus the client feels the process was a failure and the adult services experience failure in care provision because they are not resourced to support this complex population and are not prepared to adapt services to meet the populations needs. Therefore the access to health care becomes a negative and unrewarding experience for the client and health professional, resulting in the client not accessing services which could help maintain health and independence.</p>
<p>9. Miles, K., Edwards, S. & Clapson, M. (2004). Transition from paediatric to adult services: experiences of HIV-positive adolescents. <i>AIDS Care</i>, 16(3), 305-314.</p>	<p>Questionnaire and focus groups. Level III - 3</p>	<p>Small preliminary study investigating adolescent experiences of transition for those young people affected by HIV.</p> <p>“Neither simple transfer to adult services nor allowing adolescents to “drop out” of medical care is considered acceptable care for young people with chronic illness” Viner, 1990.</p>	<p>Key Findings:</p> <ul style="list-style-type: none"> ▪ Introducing adult service providers to the care of the adolescent within the paediatric unit was considered by the majority of the participants to be beneficial and fundamental to future transition preparation. (Direct transition model) ▪ Highlighted the importance of preparing the adolescents for the realities of the adult population. ▪ Co-ordinate planning where individuals have other specialised care requirements. ▪ Strongly affinity with paediatric staff lead to a reluctance to move to adult services. Concern that this was also related to paediatric staff not wishing to “let go” and not trusting the independence of the adolescent and skills of the adult services. These differing views highlighted the variability of “readiness” to transition within this population and emphasis the need for flexibility in timing. ▪ All participants discussed the benefits to transition, a point that needs emphasising during future transition preparation periods.

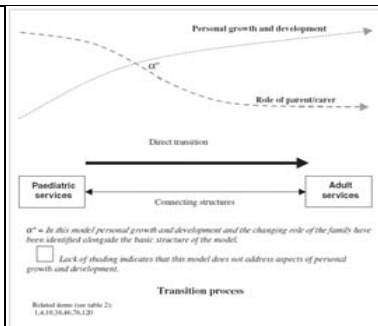
			<ul style="list-style-type: none"> Individuals need to be encouraged by the positive experiences of others, particularly surrounding the discourse of independence and control over care and treatment decisions. Development of specialist adolescent clinic to augment the transition process. This can be regarded as a “sequential model” of transition care. The safe and successful transfer to adult care is not the end of the transition process. Health professionals need to work with the adolescent to develop skills for managing their condition more independently. Further work is required to address the needs of the parents and carers during adolescent and service changes, where there is a shift in emphasis from the family-centred approach to one that is traditionally familiar with an adult, one-to-one approach to care.
10. O’Connell, B., Bailey, S. & Pearce, J. (2003). Straddling the pathway from paediatrician to mainstream health care: Transition issues experiences in disability care. <i>Australian Journal of Rural Health</i> , 11, 57-63.	Focus Groups Level III - 3	<p>This paper investigated the strengths and limitations of health care and related services provided to young adults with disability during the period of transition from the care of a paediatrician to the mainstream health system.</p> <p>12 10-person focus groups were conducted to explore these issues. They contained clients, carers and health providers of services to the paed. population.</p>	<p>Key Issues:</p> <ul style="list-style-type: none"> During discharge from the care of a paediatrician and transition from special school or mainstream integrated school, this population of young adults with a disability experience a health decline. Most young adults with disabilities require care that frequently involves multiple health care providers. And co-ordination and access to these services have been reported to be more difficult when adolescents reach adulthood. Barrier to accessing health care was the lack of finding an adult health care provider trained in paediatric conditions. Neither the young disabled people nor their carers felt that the general practitioner would be the ideal person to consult on matters related directly to their disability. As a result of these types of perceptions, young adults with a disability and their families often lack confidence in the knowledge base of providers and remain reluctant to seek out health care services until they require remedial medical attention. Literature provides support for a “shared care” model as a means to overcome communication and coordination difficulties in service delivery and to promote greater patient participation in their own care. <p>Key Findings from Focus Groups:</p> <ul style="list-style-type: none"> No equivalent service in adult health services. Communication links between health care professionals and other service providers were lacking. GP’s lack the necessary knowledge and skills of a paediatrician to be able to take on their role once the client reaches adulthood. Lack of cohesive and current information on services available for these young adults, especially with the transient nature of NGO funding and service set up. Health system relies heavily on carers to manage overall care of young adults with disability. Concern that as young people get older availability of services decreases. Carer’s perceived that the mainstream health system was geared to respond to crisis rather than to provide pro-active advice or service. Carer’s tended to find out information or resources by default rather than by intention. Young people with a disability wish to be treated as adults; being made to be more independent and involved with the decision making about their care. Increased costs associated with accessing adult health services. Young people valued services that helped them problem solve relationship and sexuality issues including contraception advice. Young people with disability need social areas, outside and apart from their family.
11. Betz, C.L (2007). Facilitating the Transition of Adolescents with	Questionnaire Level III - 3	The article provides an overview of the salient issues that adolescents with developmental disabilities face as they approach adulthood. Transition assessment, planning and intervention	<p>Transition into adulthood for adolescents with DD, particularly those with cognitive disabilities can be especially challenging as they face numerous obstacles to achieving the developmental tasks of adolescence and those of early childhood. There are a number of developmental tasks associated with adolescence that are the necessary building blocks for transitioning to adulthood.</p> <ul style="list-style-type: none"> Establishment of a sense of identity including self-concept and body image.

<p>Developmental Disabilities: Nursing Practice Issues and Care. <i>Journal of Pediatric Nursing</i>, 22 (2), 103-115.</p>		<p>strategies that can be integrated into a comprehensive plan of care are discussed.</p> <p>It identifies that health care transition differs from education transition in that it focuses on concerns relating to the youth's special health care needs and primary health care needs.</p>	<ul style="list-style-type: none"> ▪ Learning to assume greater responsibility for academic endeavours. ▪ Planning seriously for a career. ▪ Learning social rules of conduct. ▪ Developing a personal moral code of behaviour. ▪ Engaging in responsible sexual behaviours. <p>Essential features of transition best practices model for education transition:</p> <ul style="list-style-type: none"> ▪ Family involvement ▪ Interagency and interdisciplinary collaboration ▪ Self-determination skills ▪ A transition plan that includes work-based experiences in inclusive settings <p>Essential features of transition best practices model for health transition:</p> <ul style="list-style-type: none"> ▪ Transfer of care from paediatricians and paediatric service providers to adult services ▪ Acquisition of knowledge and skills necessary to independently manage daily treatment regimes. ▪ Learning to identify and advocate for accommodations needed to function more effectively in the work or school environment. ▪ Being referred to transition and adult community agencies and resources based on the individual's need for services. <p>It was also noted that students' lack of skill and self-confidence adversely affected their participation in the IEP and in transition planning.</p> <p>A primary barrier to successful transitioning was the lack of coordination between services and systems, placing the onus of responsibility to navigate these areas on the shoulders of the carers and clients who felt that they did not have the skills or knowledge to do so.</p>
<p>12. Dovey-Pearce, G., Hurrell, R., May, C., Walker, C. and Doherty, Y. (2005). Young adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. <i>Health and Social Care in the Community</i>, 13(5), 409-419.</p>	<p>Questionnaire and focus groups. Level III - 3</p>	<p>The study is aimed to describe and understand the considered opinions of 19 young adults with diabetes who were receiving secondary care services about the provision of diabetes services for young people. Findings were based on semi structured interviews and focus group methods.</p>	<p>Key issues to address when developing services for young people:</p> <ul style="list-style-type: none"> ▪ Providing consistent and relevant information on diagnosis and prognostic features of conditions. ▪ Providing continuity of staff contact to facilitate increased trust and familiarity with health care professionals. ▪ Tailoring information to the needs of the younger person, if the information is perceived as being relevant to their lifestyle they are more likely to act upon it. ▪ Fast transfers to adult services without any transition process generate feelings of negativity associated with health care. ▪ Promote self-care activities in relation to chronic condition. ▪ Develop age-banded clinics, as this would be less stigmatising and more navigable for the younger person. Allows the opportunity for health professionals to provide age-specific specialist information and developmentally tailored care. ▪ Provide positive interactions characterised by: consistency of contact, civility and rapport, listening, involving the person in the consultation and giving them choices, a non-judgemental and encouraging approach, giving positive as well as negative feedback, facilitating coping skills and access to specialist information, whole-person care facilitated by multidisciplinary teams, and age-appropriate shifts in consultation style. ▪ Addressing access and environmental concerns eg; travel times, waiting times, relevant information in waiting rooms.
<p>13. McDonagh, J.E. (2004). Growing up and moving on: Transition from pediatric to adult care. <i>Pediatric</i></p>	<p>Literature Review</p>	<p>The development of transition care is one of the major challenges of the twenty-first century as the survival rates and medical outcomes for child and adolescent recipients of transplants continue to improve.</p>	<p>It is important to emphasize that transfer to adult care is only a single event during the much longer process of transition. It is also not the terminal event of transition, which continues into adult centred care. Transition is the concern of both adult and paediatric providers and the development of this process require collaboration between services.</p> <p>Table 1. Aims of transition</p> <ol style="list-style-type: none"> 1. To provide high quality, coordinated, uninterrupted healthcare which is patient-centred, age and developmentally appropriate, culturally competent, flexible, responsive and comprehensive

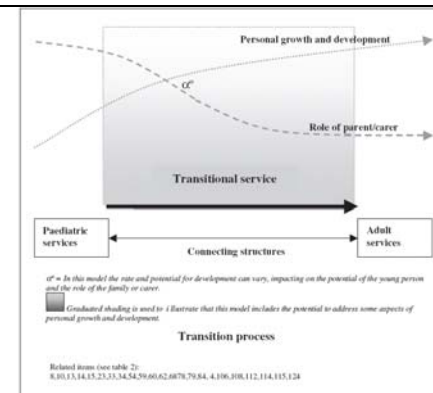
<p><i>Transplantation</i>, 9, 364-372.</p>		<p>Transition is a multidimensional process with transfer to adult only one event within that process. Successful transition is likely to require training of professionals in both adult and paediatric services.</p> <p>The paper is to present the philosophy of transition and an evidence-based approach to transition care in terms of the needs for it, proposed models of care and the evidence of the benefits of transitional care programmes. Its also explores potential barriers to successful transition.</p>	<ol style="list-style-type: none"> 2. To promote skills in communication, decision-making, assertiveness, self-care, self-determination and self-advocacy 3. To enhance sense of control and interdependence in healthcare 4. To maximize life-long functioning and potential 5. To support the parent(s)/guardian of the young person during transition and in particular to enhance their advocacy skills <p>Table 2. Key elements of transitional care</p> <ul style="list-style-type: none"> ▪ An orientation that is future focused, proactive and flexible ▪ An early start! ▪ A key worker identified for each individual patient ▪ A written transition policy agreed by all members of the multidisciplinary team and target adult services ▪ A flexible policy on timing of events with anticipation of change ▪ An approach which fosters personal and medical independence and creative problem solving ▪ A preparation period for patient and parent ▪ An education program for patient and parent which addresses medical, psychosocial and educational/vocational aspects of care ▪ A written individualized health care transition plan by age 14 created with the young person, their family with regular review and update ▪ Liaison personnel in both paediatric and adult teams ▪ A network of relevant local agencies and target adult services ▪ Administrative support including provision of medical summary that is portable and accessible ▪ A training program for paediatric and adult team members ▪ Primary and preventive care involvement and provision ▪ Affordable continuous health insurance coverage (if applicable) for all young people with special health care needs throughout adolescence and adulthood <p>The timing of transition is essentially individual for each client with respect to his or her developmental and cognitive development. Unfortunately this need of services to be flexible is often problematic as most services have age cut of points etc. Literature indicates that the consumer's have mixed views with regard to transition. Some have a positive view and outlook towards being more independent and in control of their health care. Whereas others are fearful of the unknown and change in support / service descriptions.</p> <p>Table 3. Timing of transition and transfer</p> <ul style="list-style-type: none"> ▪ Chronological age ▪ Maturity: physical and cognitive ▪ Current medical status ▪ Adherence to therapy ▪ Independence in healthcare ▪ Preparation of young person and family ▪ Readiness of the young person ▪ Readiness of the parent/guardian ▪ Availability of an appropriate adult specialist <p>There is no evidence of which transition model is preferable in terms of patient satisfaction, cost-effectiveness and outcomes. Condition specific and generic transition programs exist, the latter of which recognised that many issues faced by adolescents with chronic conditions are generic. Young people have reported that they prefer to meet with the adult teams prior to transition occurring. Time considerations need to be made when designing a transition program as paediatric consultation times are usually longer than adult. Time needs to be provided to assist clinicians explore seeing the client independent of the carers,</p>
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			<p>exploration of their “hidden agendas”, health promotion opportunities and self-advocacy skills training in addition to addressing the needs of the carers.</p> <p>Models of Transition:</p> <ul style="list-style-type: none"> ▪ Direct Transition: A single step model from a paediatric to an adult clinic with or without communication and information sharing. ▪ Sequential transition: A intermediary step model between the paediatric and adult clinics including one or all of the following: <ul style="list-style-type: none"> ○ A transition clinic ○ An adolescent clinic ○ A young adult clinic <p>This model often includes development of new services</p> <ul style="list-style-type: none"> ▪ Developmental transition <ul style="list-style-type: none"> ○ With skills training and development of support systems ▪ Professional transition <ul style="list-style-type: none"> ○ With transfer of expertise between paediatric and adult sectors <p>Potential Barriers to Successful Transition:</p> <ul style="list-style-type: none"> ▪ Time ▪ Training of Professionals involved ▪ Financial, eg. Insurance, resources for service provision ▪ Different perceptions of young person, parents, providers ▪ Attitudinal ▪ Discomfort of professionals involved ▪ Lack of application ▪ Difficulty accessing resources ▪ Poor intra-agency coordination ▪ Poor interagency coordination ▪ Difficulties addressing parental issues ▪ Adolescent resistance ▪ Lack of institutional support ▪ Lack of planning ▪ Lack of appropriate adult specialists
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<p>14.</p> <p>While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L. and Griffiths, P. (2004). Good practices that address continuity during transition from child to adult care: synthesis of the evidence. <i>Childcare, Health & Development</i>, 30 (5), 439-452.</p>	<p>Systematic Review Level I</p>	<p>This paper is aimed at identifying practise that promotes continuity at transition between child and adult services. It conducts a systematic examination of the evidence from two search strategies yielding 5319 items.</p> <p>3 of the 126 appraised items, which contributed to good practice in transition, had strong external validity. A large range of different practices, which focussed on the service, the young person and the family were identified. Practices within the service addressed structural, process and outcome components.</p> <p>Four transition models were proposed for testing.</p>	<p>Improvements have occurred in the provision of health services to children and families, however these improvements are not being sustained during the difficult transitional period from child to adult health services. While this may be due to a lack of specialised adult services, it could also be the result of a failure to manage and integrate care effectively during transition. This results in a significant number of young people becoming dislocated from the health system during this period.</p> <p>Factors that are influential in the transition from child to adult care:</p> <ul style="list-style-type: none"> ▪ Current service organisation and experience of it. ▪ Stability of condition. ▪ Duration of disability/ill health. ▪ Disability/ill health experience. ▪ Disorder treatment, adherence and experience. ▪ Complications. ▪ Support sources/access. ▪ Peer Group. ▪ Relationship to parents/partner. ▪ Demographics. ▪ Experience of the transition from childhood to adulthood. ▪ Psychological factors. ▪ Relationship to care services. ▪ Organisation of transferring. <p>Key components of “good” practice:</p> <p><u>Regarding Young People:</u></p> <ul style="list-style-type: none"> ▪ Specific service provision ▪ Development of skills of self-management and self-determination ▪ Support for psychosocial development ▪ Involvement of young people ▪ Peer involvement ▪ Support for changed relationships with parents/carers ▪ Provision of choice ▪ Provision of information ▪ Focus on the young person’s strengths for future development <p><u>Regarding Parents and Carers:</u></p> <ul style="list-style-type: none"> ▪ Support for adjustment to changed relationships with young people ▪ Parental involvement in service planning ▪ Family-centred approach ▪ Provision of information <p>Transition Models:</p> <p><u>Direct Transition Model:</u></p> <ul style="list-style-type: none"> ▪ Transition is achieved when the young person is transferred to adult care safely and efficiently. ▪ Emphasis of the model is on structural factors such as good communication and information sharing. ▪ Focus is primarily on relationships between services and addresses continuity of information and cross boundary and team continuity.
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- Probably an adequate model where the disease or disability has minimal impact on the young person's ability to develop naturally using existing resources and support systems to manage in an adult care environment.
- May also be appropriate where the young person's role in their care provision is unlikely to change significantly.



Sequential Transition Model:

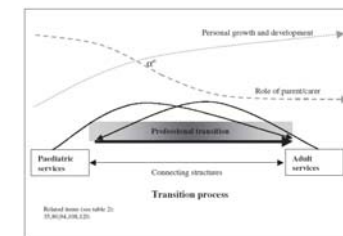
- Services and care are constructed recognising that the young person's needs are changing and that they require some preparation if they are to adjust to adult care successfully.
- Services are constructed as an extension of child provision or jointly between adult and child providers.
- In this model flexibility and longitudinal continuity are addressed.
- This model is important when the young person's role and responsibilities for care are likely to change significantly.
- The service structure and care should be distinct from child-orientated care and allow the young person to rehearse and prepare for adult based care.
- Aim is to assist the young person become an "expert" with regard to their condition, which may involve redefining the family role with the young person being given increasing autonomy in clinical decision making, eg where the young person has diabetes mellitus.

Developmental Transition Model:

- This model starts from the premise that the young person will need some help in acquiring the skills and support systems necessary to use or experience adult care effectively.
- It is based on the sequential model with an active focus on personal growth and development with the transition.
- Will involve re-defining the family's role in care provision in parallel with personal development.
- This model has most relevance regarding services for vulnerable young people and those with physical disabilities or learning difficulties.

Professional Transition Model:

- This model is distinct from the others as its focus is on the how the professional



Other supportive documents:

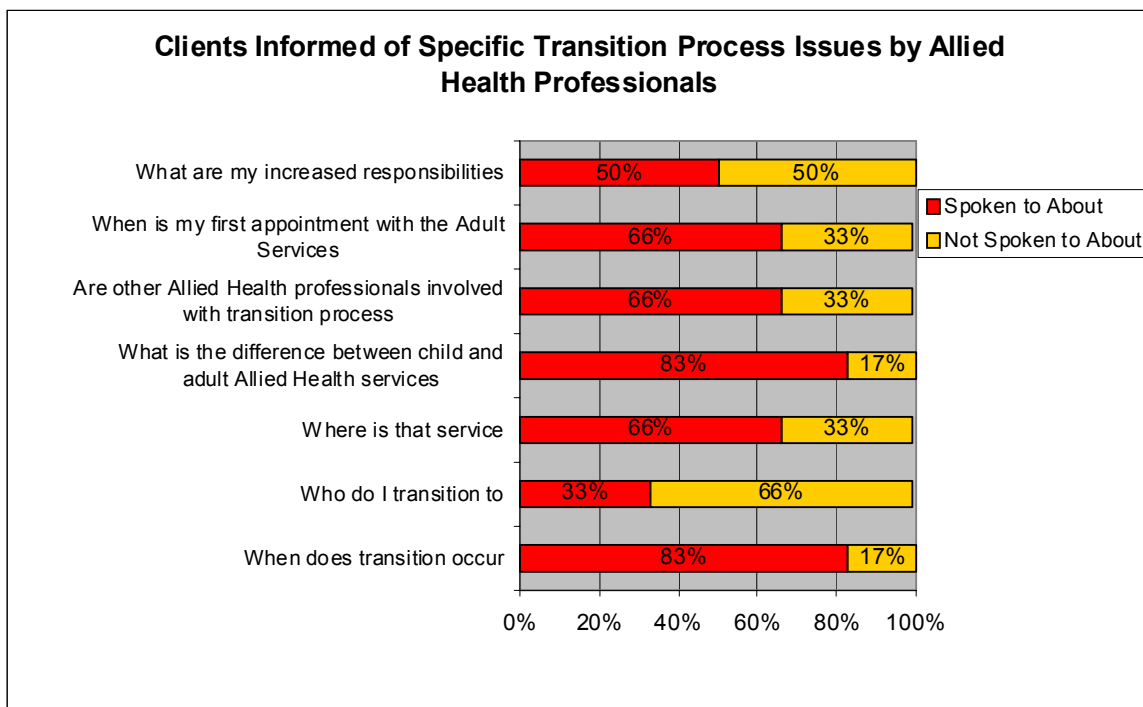
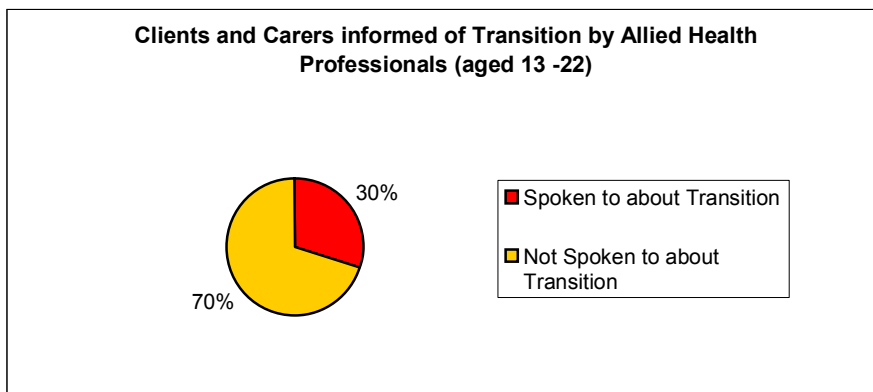
Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L. & Griffiths, P. A multi-method review to identify components of practice, which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. *Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). March 2001.*

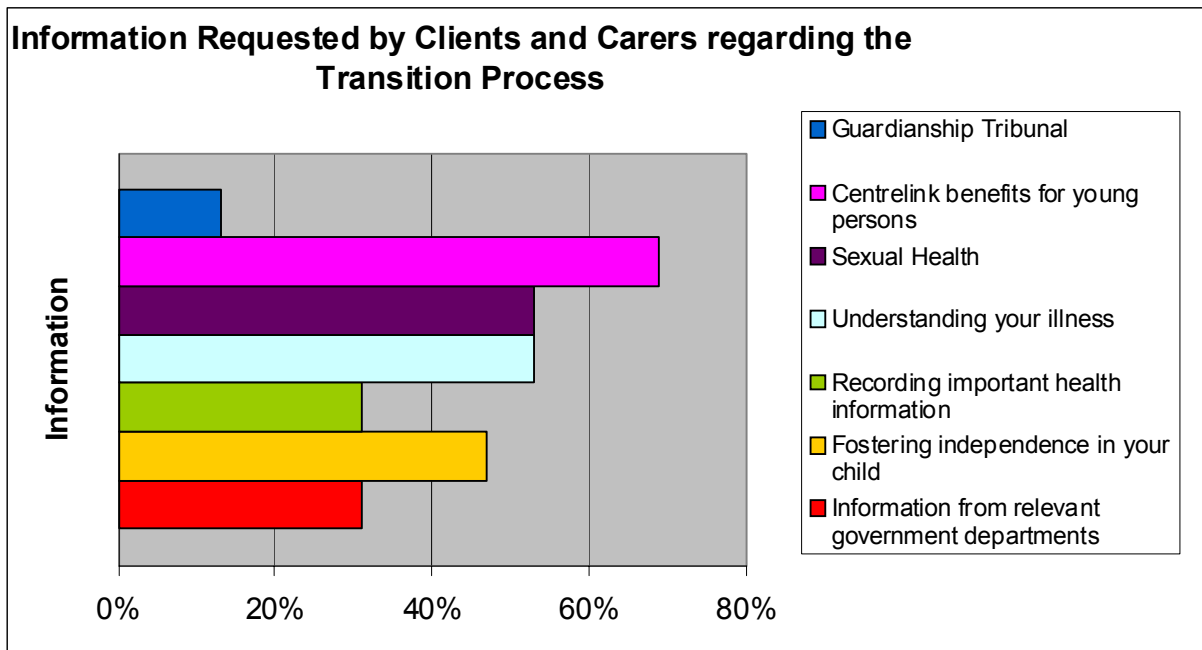
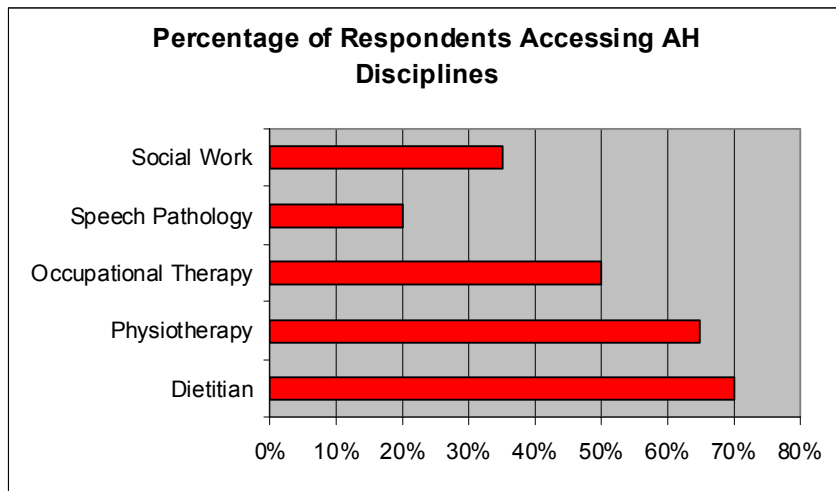
Sloman, F. Transfer of Young Adults with Complex Medical Needs Project. *Funded by Continuing Care and Clinical Service Development Section, Programs Branch Metropolitan Health and Aged Care Services, Department of Human Services, Victoria, Royal Children's Hospital. June 2005.* <http://www.rch.org.au/transition>

NH&MRC Levels of Evidence:

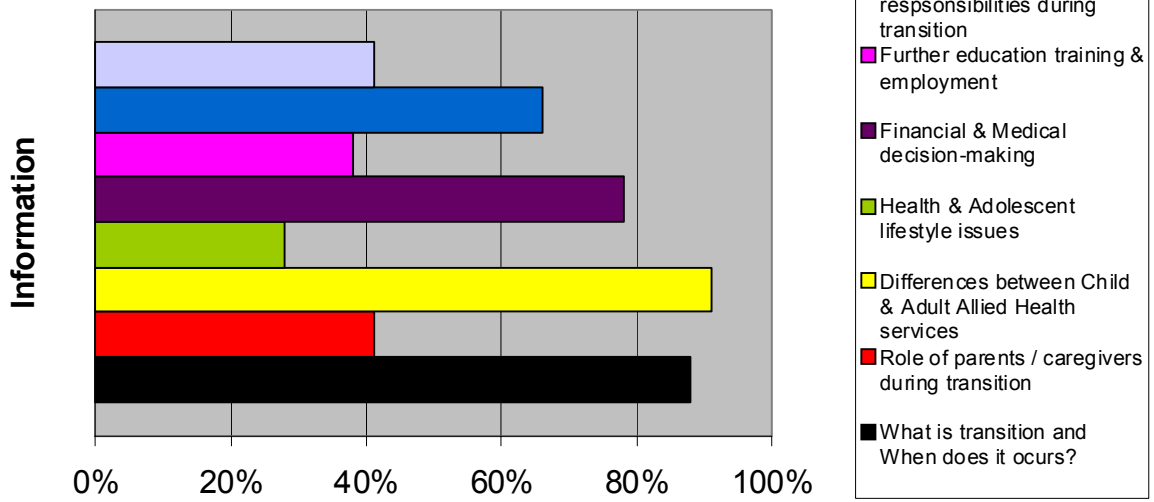
LEVEL	
I. I.	Evidence obtained from a systematic review of all relevant controlled trials
I. II.	Evidence obtained from at least one properly designed randomised controlled trial
I. III.	<ol style="list-style-type: none">1 Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation or some other method)2 Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group3 Evidence obtained from comparative studies with historical control, two or more single-arm studies or interrupted time series without a parallel control group
IV.	Evidence obtained from case series, either post-test or pre-test and post-test

APPENDIX 2 – Client and Carer Questionnaire Results



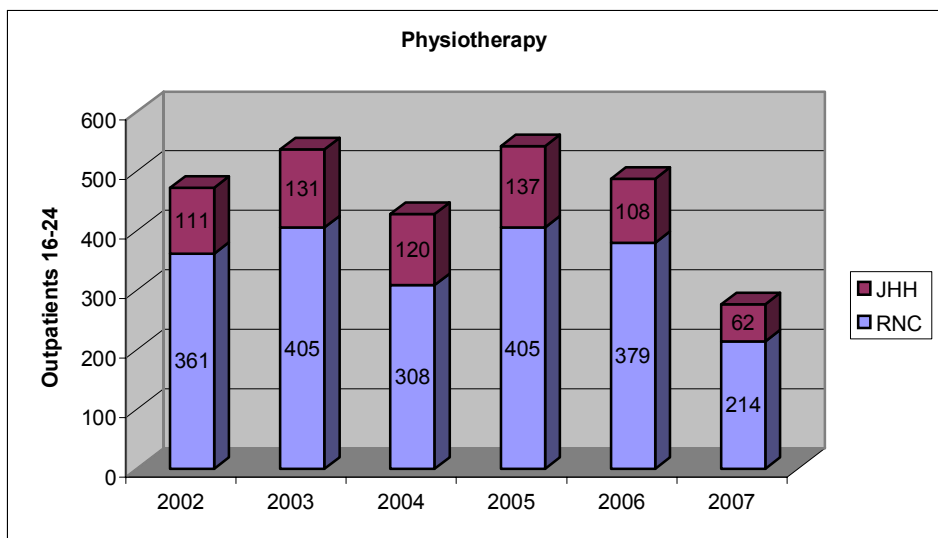
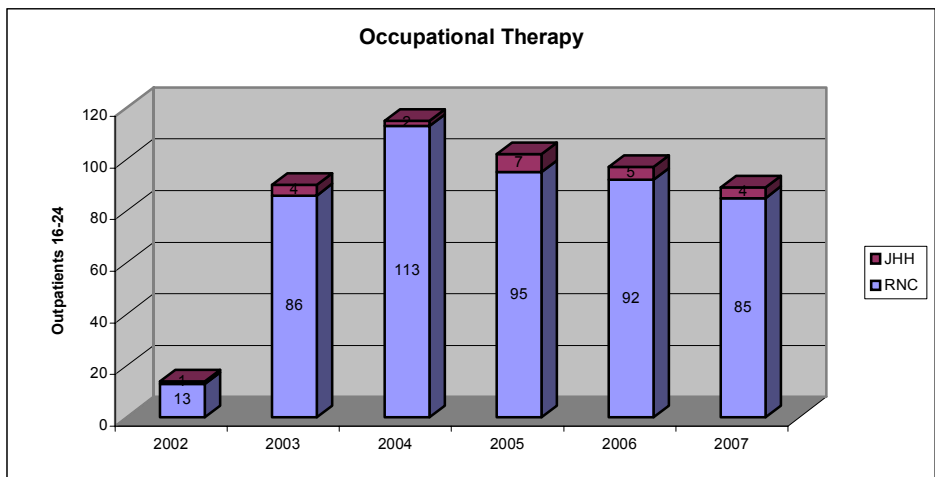
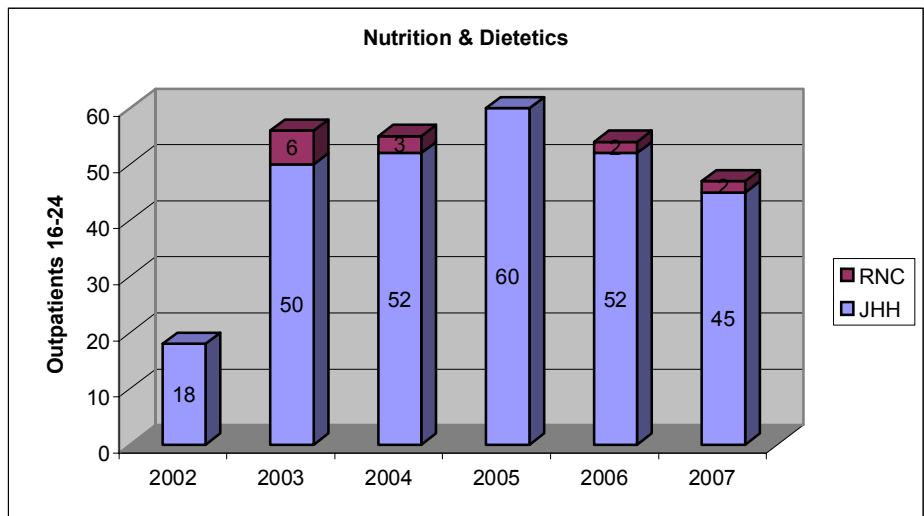


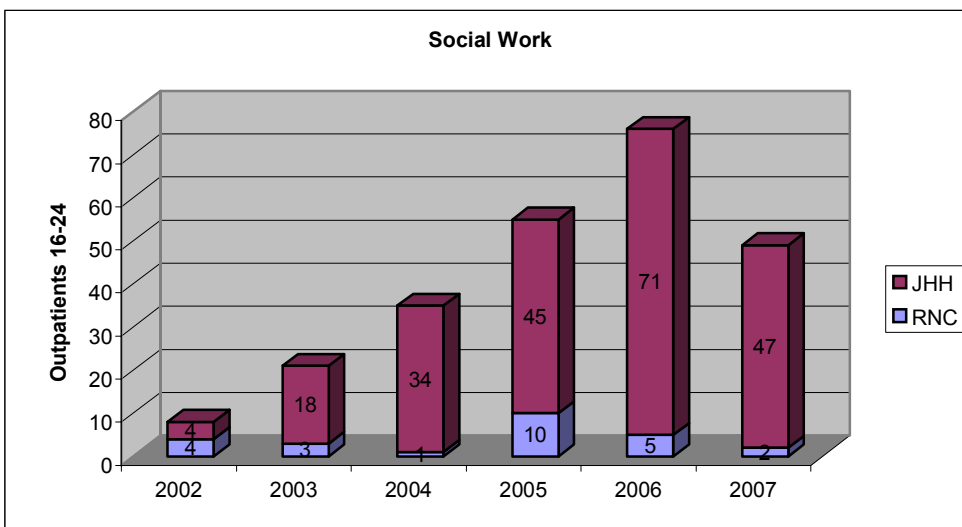
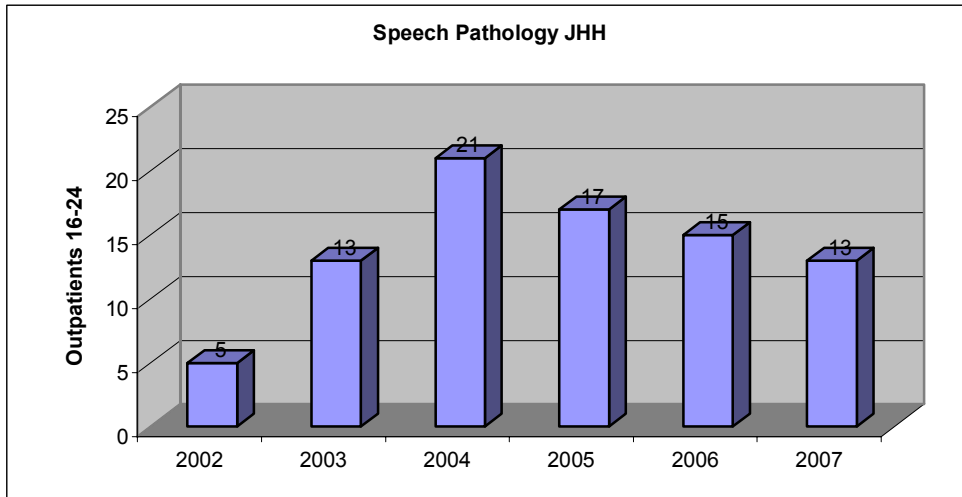
Information requested by Clients and Carers regarding Transition Process



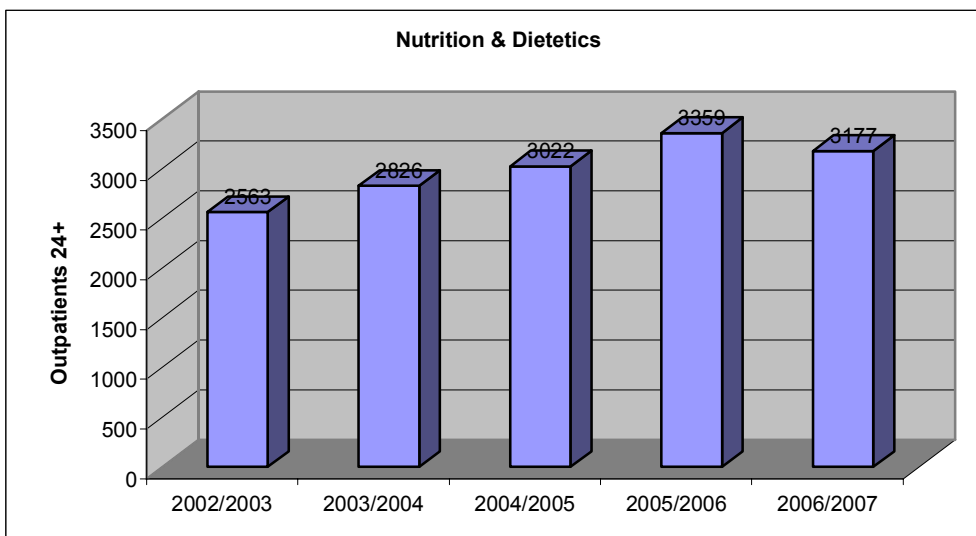
Appendix 3 - Adult Allied Health Outpatient AHMIS data.

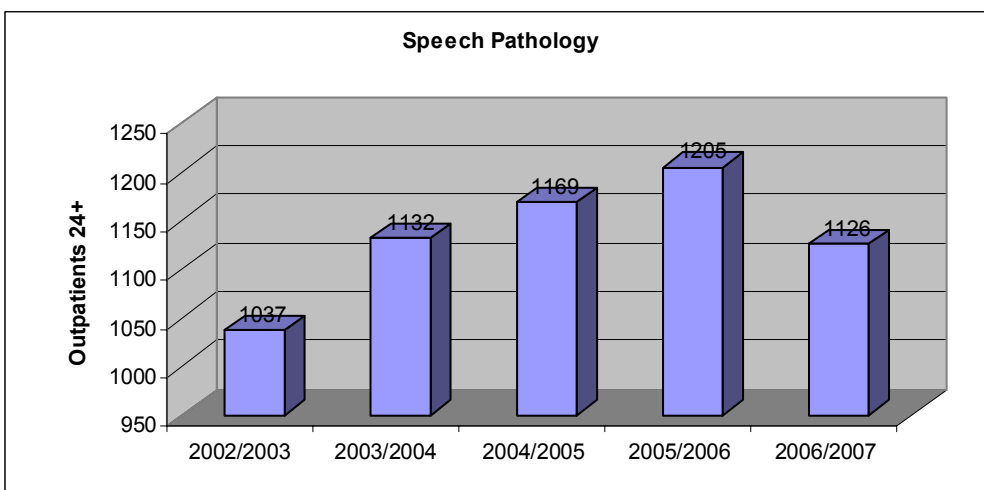
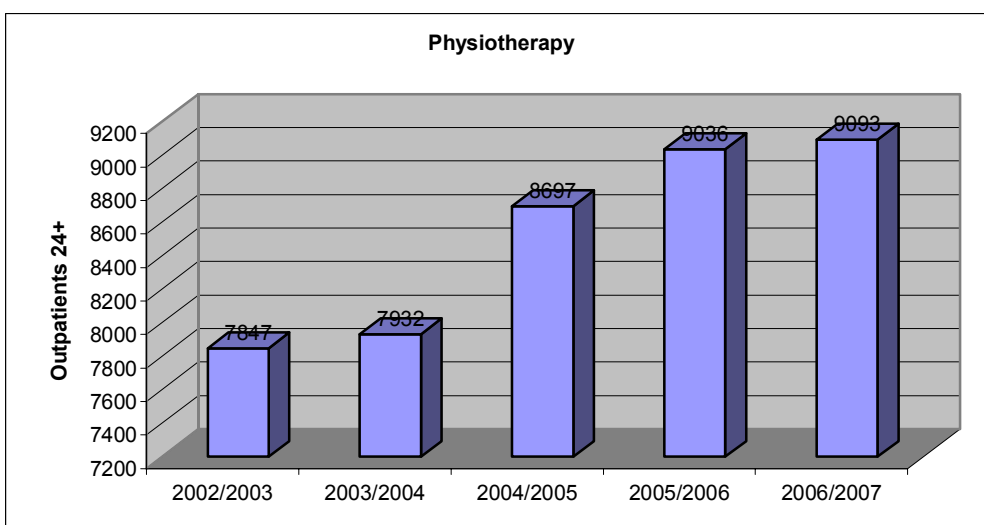
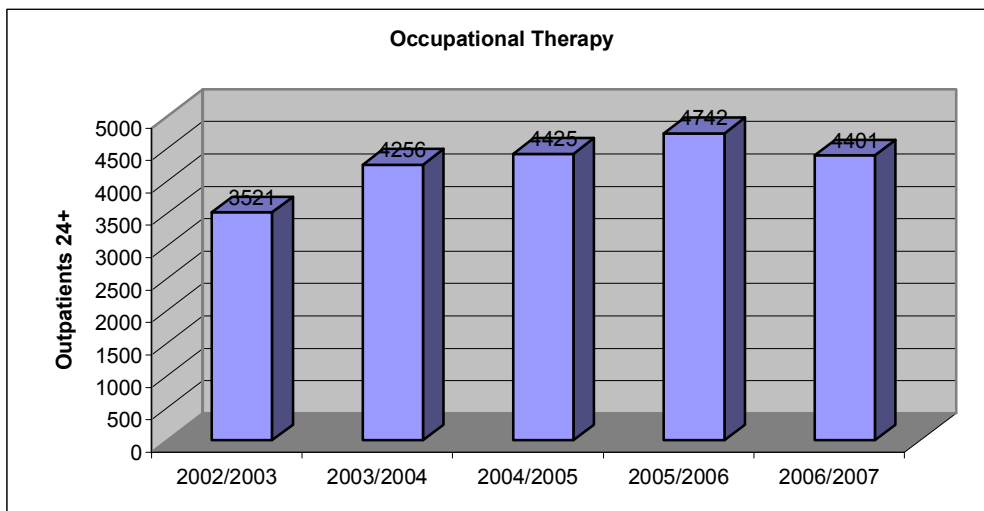
Referrals by Discipline and Site for Young Adults (16 – 24) from 2002 – June 2007

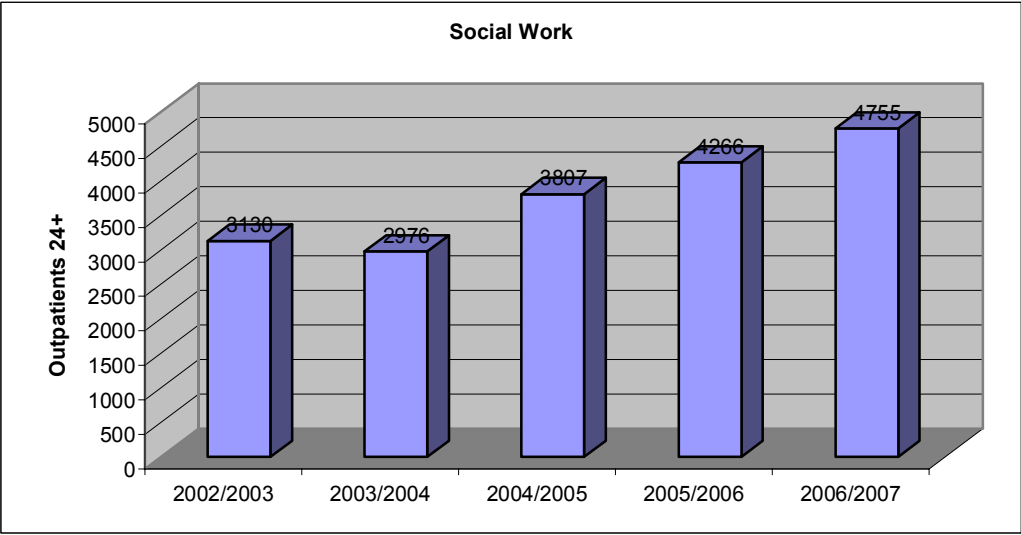




Referrals by Discipline at JHH & RNC for Adults (24+) from 2002 – June 2007







APPENDIX 4 – List of Related Resources

Greater Metropolitan Clinical Task Force – Transition Care Website accessible through HNE intranet:

www.health.nsw.gov.au/gmct/transition

GMCT Transition Care Co-ordinator HNEAHS referral form:

http://www.health.nsw.gov.au/gmct/transition/factsheets/referral_oct2005.pdf

Victorian Health “Report Transfer of Young Adults with Complex Medical Needs Project” 2005, Royal Children’s Hospital:

http://www.health.vic.gov.au/subacute/transfer_young.pdf

Victorian Health, Royal Children’s Hospital Transition Website:

http://www.rch.org.au/transition/patients.cfm?doc_id=8144#Adult_hospital_cli

Victorian Health, Client Health Care Checklist:

<http://www.rch.org.au/emplibrary/transition/HealthCareSkillsChecklist.doc>

Disease Specific Transition Models currently in place at JHCH:

- a. Cystic Fibrosis Transition Checklist
http://www.health.nsw.gov.au/gmct/transition/factsheets/checklist_cystic_fibrosis.pdf
- b. Diabetes Transition Checklist
http://www.health.nsw.gov.au/gmct/transition/factsheets/checklist_diabetes.pdf
- c. Spina Bifida Transition Checklist
http://www.health.nsw.gov.au/gmct/transition/factsheets/checklist_spina_bifida.pdf
- d. Neurology Transition Checklist - JHCH

APPENDIX 5 – Executive Working Party

Lynne Brodie – GMCT Transition Care Executive

David Rhodes – Allied Health Director, HNEAHS

Jenny Martin – Allied Health Manager, Kaleidoscope Children’s Services, HNEAHS

Amanda Orr – Head of Discipline, Occupational Therapy, Kaleidoscope Children’s Services, HNEAHS

Rebecca Harris – GMCT Transition Care Co-ordinator, HNEAHS

Tracey Finn – GMCT Transition Care Co-ordinator, HNEAHS

Karen Johnson-Dewit – GMCT Transition Care Co-ordinator, HNEAHS

APPENDIX 6 – Transition Guidelines for Allied Health Disciplines in GNS



Kaleidoscope / Greater Newcastle Sector Allied Health Transition Project Guidelines for Transition Process in Allied Health Services in GNS

Contents:

1. Background
2. Guidelines Brief
3. Key Considerations for Transition
4. Tools to assist with Transition Planning
5. Guidelines for Transition Process
 - a. Initial Transition Stage
 - b. Intermediate Transition Stage
 - c. Final Transition Stage
6. References – Literature Review: GMCT / Kaleidoscope Allied Health Transition Project 2007
7. Negotiated Agreement
8. Non-Government Organisations in Newcastle Area
 1. Background:

Discussion with clinicians across the Greater Newcastle Sector revealed a need for development of Transition Process guidelines / procedures for Allied Health (AH) disciplines in the HNEAHS. An interim guideline policy for Kaleidoscope HNE services is currently being ratified. This document supports the need for AH disciplines to develop transition care procedures for their caseloads.

Data collected from AH clinicians and clients involved with this project indicated that they need defined Transition Process Guidelines to assist with:

- a. Clinicians, clients and carers understanding that transition is a process not simply transferring care to adult services.
- b. Clinicians being empowered with knowledge to implement a process that is evidence-based and supported by management.
- c. Providing structure to a process that can be easily misinterpreted by clinicians, clients and carers alike and also management.

See "Kaleidoscope (GNS) / GMCT Allied Health Transition Project Final Report 2007" for more detailed questionnaire results.

2. Guidelines Brief:

The following document is designed to provide a framework for AH departments in the GNS area to develop their own Transition Process procedures that are specific to their disciplines' needs. It refers to existing GMCT Transition Care resources that are generic to clients with chronic conditions and offers a further explanation of the importance of transition care with respect to AH services in the Newcastle region. The information is referenced and a list of relevant existing resources is provided to help departments generate their own procedures.

Each transition stage is further broken down to provide clinicians with information on general therapy areas to target, carer goals and client goals to assist with facilitating transition for this heterogeneous population.

It is acknowledged that existing services for young people with chronic conditions are limited in the GNS area. These guidelines are designed to be implemented with respect to existing services and development of services in the future. Regardless of where the client is transitioned to, the underlying principles of transition, that of; information exchange, health professional collaboration, client and carer skill and knowledge development and client enablement remain consistent.

References (1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16.)

3. Transition Standards:

- ❑ **Understand that “transition” is different to “transfer”. In that “transition” is the planned, organised and co-ordinated movement from one service delivery model / provider to another, where as “transfer” is simply the movement.**
- ❑ **Ensure the process is developmentally appropriate for the client.**
- ❑ **Ensure the client and carer/s are directly involved with the process.**
- ❑ **Ensure the client and carer/s are informed and understand the process.**
- ❑ **Educate AH clinicians to be able to successfully implement the process and provide clinical and managerial support to do so.**
- ❑ **Educate the client and carer/s about the role of Allied Health services in the adult system. Ensure that they understand what each discipline can offer them and when it is appropriate to access their services.**
- ❑ **Start the transition process early to allow for the client and carer/s to develop the skills necessary to navigate adult AH services.**

- **Ensure regular case conferences occur between treating AH professionals to facilitate communication of transition planning.**

(References: 1, 2, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16)

As per:

GMCT Transition Network: Generic Standards for Transition

Adapted from the 2007 project - Standards of Cystic Fibrosis Care in Australia developed by Cystic Fibrosis Australia and the CF special interest group of the Thoracic Society of Australia and NZ

- | | |
|--------------------|---|
| Standard 1 | Transition is a process that requires close collaboration between paediatric and adult specialist care teams. |
| Standard 2. | All young people with chronic illnesses and disabilities arising in childhood/adolescence should have a transition programme and the process should engage young people and their family in a positive way. |
| Standard 3 | The process of transition should begin around the time of secondary school entry (age 12) and finish around school leaving time (18 years). |
| Standard 4 | Paediatric and adult specialist teams should develop a transition plan and meet to discuss individuals in transition. |
| Standard 5 | A case manager should be designated. Opportunity should be provided for the young person and their family to meet the adult team prior to transfer. |
| Standard 6 | A comprehensive summary of medical and social issues should be available to the adult team well in advance of transfer. |

4. Tools to assist with Transition Planning:

1. Negotiated Agreement (see section for professionals on transition website www.health.nsw.gov.au/gmct/transition)

- Developing a contract between the clinician and the client.
- Aim is to assist the client and carer change behaviours to improve their health.
- Used to define goals and expectations of members of treating team and client and carer/s.
- Copy in Appendix B.

2. GMCT Transition Planning Checklist (found on Transition Care website as above)

- This resource is not specifically geared towards Allied Health but has ideas that should be discussed and considered at each stage of transitioning.
- This resource can be easily adapted by clinicians to meet the individual needs of clients and carers.
- Some of the sections may be more appropriately managed by different Allied Health professionals; eg “Sexual Health” by a social worker and “Educational and vocational planning” by an occupational therapist.
- “Other useful link”, under “G” and “Greater Metropolitan Clinical Task Force”.

3. GMCT “Making the Move: Checklist for Young People” found on the GMCT website

- This resource is not designed for independent use by adolescents with cognitive impairments.
- However, it is worth discussing the contents with the carers and conveying the information in a more appropriate manner to the client with respect to their cognitive and communication abilities.

4. HNE Interim Guidelines

- a. Includes a generic transition model for AH services to integrate into their current practises.
- b. Includes a generic individual transition plan template for AH services to utilise.

5. Referral to GMCT Transition Program

- a. Recommended as part of the generic transition process. The GMCT Transition Co-ordinator will contact the client after transition has occurred to provide support and guidance in navigating adult health services.
- b. Referral form found at http://www.health.nsw.gov.au/gmct/transition/factsheets/referral_oct2005.pdf

6. Disease Specific Transition Models currently in place at JHCH

- a. Cystic Fibrosis Transition Checklist
http://www.health.nsw.gov.au/gmct/transition/factsheets/checklist_cystic_fibrosis.pdf
- b. Diabetes Transition Checklist
http://www.health.nsw.gov.au/gmct/transition/factsheets/checklist_diabetes.pdf
- c. Spina Bifida Transition Checklist
http://www.health.nsw.gov.au/gmct/transition/factsheets/checklist_spina_bifida.pdf
- d. Neurology Transition Checklist – The Logical Next Step; Information about transition from the JHCH Neurology Team to Adult Services

5. Guidelines for Transition Process:

The transition planning checklist developed for professionals found on the GMCT website splits the transition process into 3 stages. Each stage includes development of client and carer skills in the following areas:

- Self Advocacy
- Independent health care behaviours
- Sexual Health
- Psychosocial
- Education and vocational planning
- Health and lifestyle
- Parents / family

For transition to work well from an Allied Health perspective, collaboration between disciplines involved would be necessary to ensure that the transition process is being directed at the same pace for all intervention. Organisation of regular case conferences to discuss transition issues would also be necessary.

The following is a breakdown of each stage of transition with respect to the role of an Allied Health Professional and relevant literature.

The breakdown will include information on:

- Aim of the stage of transition
- When to start this stage
- Key client skills to develop
- Key carer skills to develop
- Role of the clinician

The listed client and carer skill acquisition is a general guide. The clinicians are encouraged to adjust the proficiency required for each skill to account for the client's cognitive, communicative and developmental needs. The underlying important goal is that the client and carers begin to modify their behaviour and interactions with AH professionals to be more in line with how the adult system functions. The more prepared our clients and carers are the more successful their transition will be.

5a. Initial Transition Stage (12-14 years):

□ **Aim of the Stage of Transition:**

This early stage of transition consists of providing education and information to the client and carer/s.

□ **When to start this stage?**

Existing transition models recommend starting this process when the client is aged 12 years (Neurological Transition Project, HNEAHS, 2006; GMCT website; References: 5, 6, 13). However, it is not clear if this is a workable age for those clients with intellectual impairments. Therefore it is recommended that the clinician adjust the delivery of such information to account for the client's developmental, cognitive and communication abilities, and that the carer is still provided with the detailed information. (References: 4, 11).

As this stage is primarily about providing information and supporting the carer to take a more active role in the clinical decision-making regarding the client, it is reasonable to suggest that it occur earlier in the client's adolescent years rather than later. As the time to adjust for each carer can be different, it is logical to assume that some will need longer than others.

□ **Key Client Skills to Develop**

- Developing understanding of disease process and symptoms
- Emerging confidence in asking the health professional questions
- Emerging understanding of the rationale for therapeutic activities
- Develop an understanding of the transition process
- Explore external support options appropriate for the young person to being establishing social and community awareness and interactions. Eg, NGO's, Internet, support organisations.

□ **Key Carer Skills to Develop**

- Develop an understanding of the transition process
- Discuss where young people and parents can obtain information about sexuality and puberty
- Explore ways to engage the client in household activities (eg, chores) to boost their self esteem, assist in taking responsibility and develop self reliance
- Discuss ways to facilitate the carer moving away from the caring role and into a facilitating role

□ **Role of the Clinician:**

The clinician should provide relevant information during this stage of transition. Such as:

1. Information on disease / condition process and progression.
2. Information on current service provision and future service provision. That is, the differences between family focussed services (paediatric) and clinician focussed / impairment based services (adult).
3. Information on the changing role of the client and carers with respect to accessing Allied Health services; eg moving towards the client and carers becoming an active part of clinical decision making and developing of therapeutic goals.
4. Information on developing self-help skills and activities for the client to boost their sense of independence and motivation towards health care.
5. **Information sharing:** key therapy goals and management plans should be documented and distributed to all stakeholders eg, GPs, school, clients and carers, other AH professionals and medical teams. This is especially relevant for clients who are not managed by a "team" (such as; Paediatric Brain Injury or Diabetes) to facilitate an organised method of managing the transition of the client.

The clinician should also begin engaging the client and carer in the clinical decision making process in a supported and guided fashion as these skills need to be well developed to assist in the transition process and will better enable the client and carer's to successfully navigate adult services. This stage should consist of introducing clinical goals that will increase the client's independence

and self-help skills, as this will have a positive effect on the clients self esteem and attitude towards managing their health condition. Research has reported that clients with intellectual and physical disabilities that were encouraged and supported in developing self-help and independence skills were more able to successfully transition to the adult services. Parents / carers also reported that they benefited from learning how to support their child / client develop more independence as it supported them to learn how to step back and facilitate as opposed to “doing” for the client.

5b. Intermediate Transition Stage (15-16 years):

□ Aim of the Stage of Transition:

During this stage of transition the role of the client and carer becomes more pro-active in the planning for transition into adult services. The client and carer practise and develop the skills needed to assist with managing and directing care more independently of the AH clinician. It should be expected that the carer and client are able to commence directing health care activities with the view towards them doing so independently in the near future.

□ When to start this stage?

It is recommended that the client and carer move into this intermediate stage of transitioning at approximately 15-16 years of age.

□ Key Client Skills to Develop

- Implement therapy goals that target skills such as: (if appropriate)
 - Making an appointment
 - Talking to strangers over the phone
 - Explaining reasons for needing services

If the client has a developmental / intellectual disability that effects their abilities to meet these goals, modify them so that the client is still developing strategies that will assist them in the adult AH services.

- Discuss / assist the client to understand when, how and from whom to seek emergency / medical help.
- Facilitate more independence at home:
 - Taking their medication
 - Be more responsible for therapy activities; i.e. include into daily routine, mark off on a daily planner, develop a reward system to encourage motivation and responsibility and ownership of therapy tasks at home
 - Have specific, achievable task to perform that establish the client's role in household management; i.e., moving the family

attitude of the client from being dependent on the family to being an active member of helping the family unit function. Eg, sorting laundry, folding clothes, sorting recycling, feeding an animal.

- Encourage leisure activities such as joining a club, attending a camp or joining a community support group to provide a balance between health and school activities.
- Commence discussions around future education and vocational options for the client.

□ **Key Carer Skills to Develop**

- Assist the carer to develop a positive attitude towards becoming more independent in managing the client's health care.
- Assist the carer to move from the "doing" role into the facilitating role with respect to their interactions with the client.
- Ensure the carer has access to all relevant information on the client's illness and management.
- Further develop their understanding of the differences between paediatric and adult AH services.
- Discuss support systems and services that the carer has access too.
- Ensure the carer is aware of youth health and mental health services available to them and the client and when to access them.

□ **Role of the Clinician:**

The clinician should be interacting with the client and carer as though they are equally involved in the clinical decision making process.

To foster the client and carer's developing independence in managing health issues the clinician should:

1. Encourage developing self-help and independent living skills and support the carers to learn how to facilitate their client's development of independence.
2. Encourage developing of skills that will improve / maintain social interactions and assist with developing peer relationships separate to

school, health care and home environments – effectively focussing on expanding the clients social sphere to help boost their self esteem and provide scope for their life focus that is outside of accessing health care and school.

3. Direct questions to the client when able to actively involve them in the clinical interview and decision-making process.
4. Encourage the client to become familiar with booking appointments.
5. Encourage the client (if able) to participate in part or all of the therapy sessions without the carer in attendance to assist the client develop the communication skills required to interact with AH professionals.
6. Encourage the client to meet with other health professionals independently to allow for opportunities to discuss issues such as sexual health / mental health issues.
7. Encourage the client to learn more about their treatment regimes and attempt to modify them so that the client can come to take more responsibility in their implementation at home.
8. Begin to discuss the currently available adult AH services that the client will need to access so that they have time to become familiar with the new names of services, referral methods and impairment based focus as opposed to family focused services.
9. **Information sharing:** key therapy goals and management plans should be documented and distributed to all stakeholders eg, GPs, school, clients and carers, other AH professionals and medical teams. This is especially relevant for clients who are not managed by a "team" (such as; Paediatric Brain Injury or Diabetes) to facilitate an organised method of managing the transition of the client.

5c. Final Transition Stage (17-18 years):

□ **Aim of the Stage of Transition:**

During this final stage of transition the client's care is transferred in a supported manner to appropriate adult services. For the client and the carers this stage is the final supported learning time for them. After transition is complete and the client is 18 years of age they are expected (by existing adult services) to be able to manage their health care in an independent fashion.

□ **When to start this stage?**

It is recommended that the client and carer move into this final stage of transitioning at approximately 17-18 years of age.

□ **Key Client Skills to Develop**

- An understanding of the adult AH services required for ongoing care; contact details, referral methods, waiting lists etc.
- An understanding of when to contact for review / assistance.
- Meeting with adult AH clinicians to facilitate developing rapport and easing client's anxieties about changing services.
- Community / support networks are established so that the client has a community network to be a part of as they become an adult.
- Educational / vocational options are established.
- The necessary documents have been completed to ensure the client has access to any Centrelink support, Medicare card, proof of age card etc.
- An independent attitude towards future health care needs with the necessary information and contacts to minimise the risk of the client ceasing to access AH services.
- A well-developed relationship with a GP who will be providing ongoing medical care and case management for the client.

□ **Key Carer Skills to Develop**

- The carer is comfortable in the role of support person not "carer" for the client, as they become an adult.
- The carer has enough information and skills to be able to encourage and support the client continuing to access AH services.
- The carer has the relevant information to assist the client access any sexual health or mental health services they may require.
- Understanding of the role of the GP in managing the client's ongoing medical needs and facilitating referrals through to required specialists in the adult health service.

□ **Role of the Clinician:**

While finding an appropriate adult service in which to transfer clients can be problematic, the clinician has a responsibility to provide the client and carers with as much relevant information on existing adult services as possible. It is acknowledged that the existing adult services are not developmentally appropriate for this caseload, however resolving that situation will take time. In the interim, the clinicians are encouraged to provide information on existing adult Allied Health services that the client and carer may need to access; eg PAPP.

Other issues that the clinician may face are the lack of consultant services available for this population. The clinician needs to be aware that the client's medical and health concerns may be primarily managed by a GP who may have limited understanding of the variety of Allied Health services available to the client. Therefore it is important for the clinician to give the client information on when and how to access adult services, as it is likely that a GP may not be able to identify early signs and symptoms of emerging difficulties. The client and carer's need to be encouraged to actively access Allied Health and medical services before a crisis situation arises that may result in hospital admissions.

To support the client to access adult AH services, the clinician should endeavour to:

1. Provide the client and carers with written information on existing adult AH services in the area that they may need to access.
2. Provide a detailed written handover / report of the clients previous treatment to the client and carer, relevant adult AH services, consultant and GP.
3. Facilitate and support the client to make their first appointment with the adult AH services. It is important that the client has an appointment with adult AH services to provide continuity of care and ensure that there is not an extended gap between accessing services, as this may create a sense of reluctance to access services when needed due to feelings of being unsupported and unfamiliar.
4. If possible the clinician should attempt to contact the adult clinician and discuss the clients treatment needs prior to this appointment.
5. If possible the clinician should attempt to be present during the first appointment with the adult clinician to help facilitate rapport building and put the client and carer at ease.
6. **Information sharing:** key therapy goals and discharge plans should be documented and distributed to all stakeholders eg, GPs, school, clients and carers, other AH professionals and medical teams. This is especially relevant for clients who are not managed by a “team” (such as; Paediatric Brain Injury or Diabetes) to facilitate an organised method of managing the transition of the client.
7. Advocate for the client to discuss the Enhanced Primary Care (EPC) Chronic Illness Management Plan with their GP. This could enable them to access ongoing AH services through the private sector and still receive a Medicare rebate. www.health.gov.au/epc.

APPENDIX 7– Non-Government Organisations in the Newcastle Area

Non-Government Organisations – Community Services

Hunter / Central Coast School Leavers Directory

<http://www.newcastle.edu.au/service/rdlo/resources/2006-2007%20H-CC%20School%20Leavers%20Directory%20V.1.pdf>.

Break Thru Employment Solutions Disability Employment Network 4922 1600	Disability Services Australia Community Participation Program 0412 003 418	MEGT (Australia) Ltd Information about apprenticeships and traineeships 4961 8888
Castle Personnel Employment Disability Employment Network 4929 7711	House with No Steps Transition to Work Program Day Programs Disability Supported Employment 4946 8311	Mission Australia Information about apprenticeships and traineeships Job Network 4940 0888
Castle Personnel (Post-school day programs) Transition to Work Program Community Participation Program 4926 3700	Job Centre Australia Disability Employment Network 4960 2200	New Horizons Disability Employment Network Supported Accommodation 4956 3299
Central West Community College Australian Apprentice Centre Information about apprenticeships and traineeships 4940 1100	JobQuest 13-19 year olds in school and assistance with transition for further education, training or employment 4929 6177	New Lake Peer Support Transition to Work Program Community Participation Program 4963 6420
Centrelink Information on Centrelink payments and services, including Indigenous Services Youth & Students 132490 Disability, Sickness & Carers 132717	Life Without Barriers Community Participation Program Transition to Work Program 4925 2630	Newcastle/Hunter Community Access Community Participation Program 4925 3000
CRS Australia Vocational rehabilitation and employment solutions for solutions for people with a disability, injury or health condition 1800 624 824	Lifestyle Solutions Transition to Work Program Community Participation Program 4967 7777	ReEmploy Disability Employment Network for people aged 15-64 with psychiatric disability 4929 3888
DADHC Transition to work and community participation programs for Year 12 students and HACC programs 4927 8422	MAS National Information about apprenticeships and traineeships 4968 4136	Response Services Incorporated Transition to Work Program Community Participation Program 4965 3533

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HNEAHS

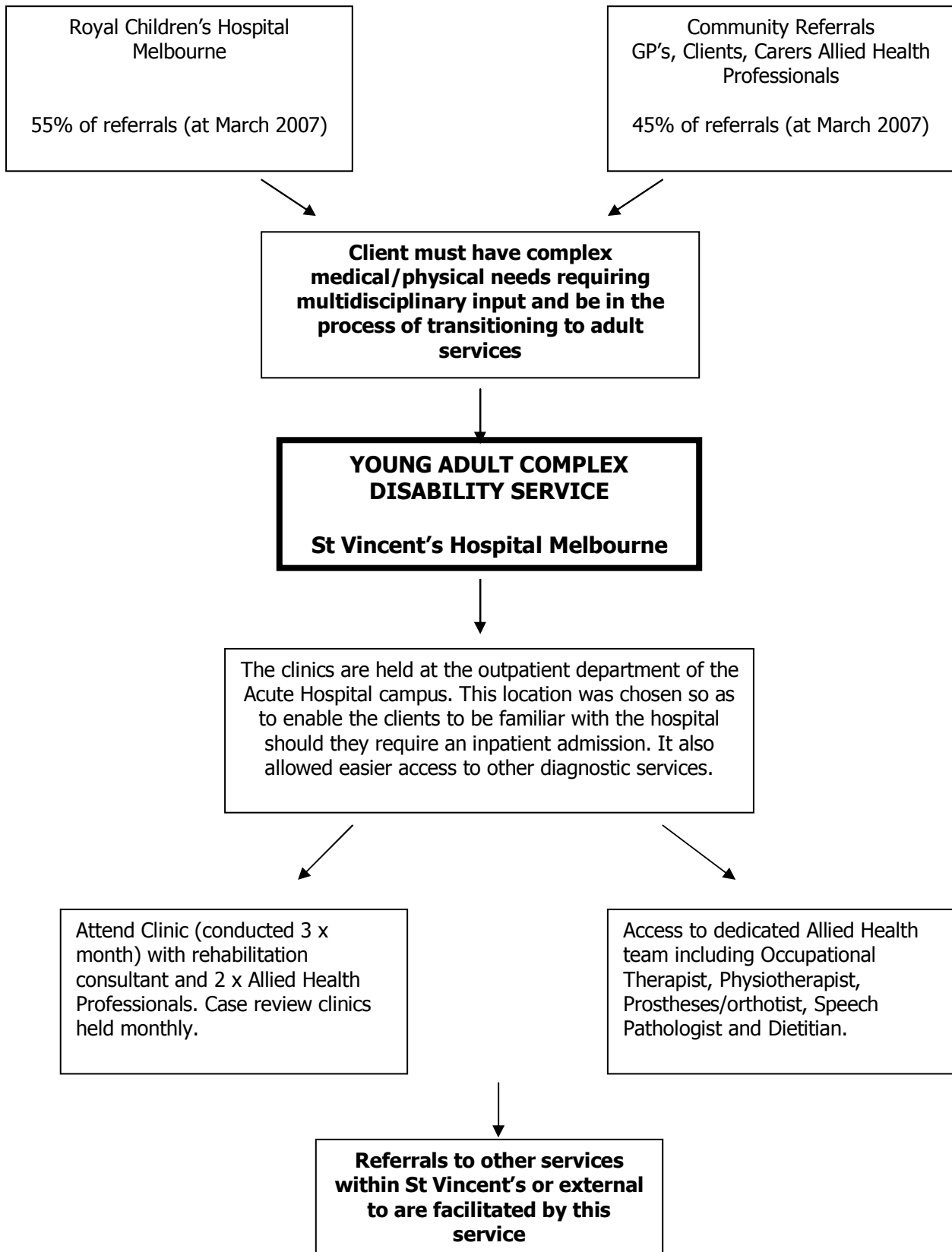
Community Services continued

Samaritans Community Participation Program 4960 3100
Sunnyfield Community Participation Program 4320 1400
The Salvation Army Employment Plus Job Network Provider 4935 8000
The Spastic Centre Community Access Service Community Participation Program Accommodation 4951 7614
Wesley Uniting Employment Job Network Provider 4955 5520
Work Directions Australia Pty Limited Job Network Provider 4060 5300
Vision Australia Transition to Work Program Disability Employment Network Training Programs in assistive technology 1300 132 560

Equipment Services	Education Services
<p>Technical Aid for the Disabled (TAD) Custom-designed aids Loan Computers Information on aids and technology to people with disabilities and staff 4946 9168</p>	<p>TAFE Information on support available for students with disabilities during their TAFE studies 4923 7944</p>
<p>TASC Customised service designed to meet the technology, seating and mobility needs of people with disabilities in NSW Allied Health Team approach Scale of charges 02 9972 8183</p>	<p>University of Newcastle Support for students with a disability during their studies 4921 5866</p>
	<p>Job Quest 13-19 year olds in school and assistance with transition to further education, training or employment 4929 6177</p>

Explanation:	
DADHC Programs Transition to Work Program	<p>Must be in Year 12 to apply</p> <p>Time-limited program aiming to support and improve employment outcomes for school leavers who can transition to work in 1-2 years</p> <p>Assists school leavers with a disability to develop skills that will help them move into employment, vocational education and training or higher education</p>
Community Participation Program	<p>Must be in Year 12 to apply</p> <p>For school leavers with a disability who have moderate to high support needs and require an alternative to paid employment, vocation education and training.</p> <p>Provides school leavers with opportunities for continued learning, life skill development and participation in the community, which increases independence and ability to meet life goals.</p>
Disability Employment Services (Centrelink) Disability Employment Network	<p>1 or more of the following:</p> <p>Support while training for a particular job</p> <p>Help in finding a job and starting employment in the open labour market</p> <p>Continuing support once you have started work</p>
Disability Supported Employment Services	Employ and support people with disabilities
Vocational Rehabilitation (CRS)	<p>Helping the individual to understand, compensate for and manage:</p> <p>Their disability, illness or injury</p> <p>The limitations or restrictions imposed by their disability</p>
Job Network Providers (Centrelink)	<p>National network of private and community organisations dedicated to finding jobs for unemployed people, particularly long term unemployed.</p> <p>Those on the youth allowance, Newstart or parenting payment are referred to a Job Network Member at their contact with Centrelink.</p>

APPENDIX 8 - Transition Clinic Model: An example of a successful transition clinic for young adults in Melbourne.



Current Staffing levels for Young Adult Complex Disability Service

POSITION	GRADE	FTE	HOURS
Visiting Medical officer		0.1	4
Service Coordinator	Grade 3 Year 4	0.3	12
Physiotherapist	Grade 3 Year 4	0.2	8
Occupational Therapist	Grade 3 Year 4	0.3	12
Prosthetist/Orthotist	Grade 3 Year 4	0.3	12
Speech pathologist	Grade 2 Year 4	0.1	4
Dietitian	Grade 2 Year 4	0.03	3 hrs per fortnight

The referral rate for this service is approximately 4 clients per month. In March 2007 there were 47 clients accessing this service predominantly presenting with Cerebral palsy (80%). In a 20-month period these 47 clients generated the following number of referrals:

SERVICE REQUIRED	NUMBER OF REFERRALS
Allied Health (see table below for referral by discipline)	60
St Vincent's Clinics (e.g. Seizure Clinic, Respiratory Clinic ENT)	32
Referral to external services (e.g. Mental Health, Dental Clinic)	31
Inpatient Admission	13

Allied Health referrals for the Young Complex Disability service:

ALLIED HEALTH DISCIPLINE	NUMBER OF REFERRALS
Physiotherapy	17
Occupational therapy	14
Prosthetist/ Orthotist	14
Dietitian	12
Speech pathology	3

This is reflective of the needs of the population accessing this service. A request has been made to increase the prosthetist hours and to employ a social worker for the service.

APPENDIX 9 - Map of Adult Outpatient Allied Health Services in the Hunter Area.

Nutrition and Dietetics: Adult Outpatient Services

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Ambulatory Care Services	RNC	Specialty Clinics by caseload	Referral Management Centre 49257990	Cheryl Watterson 49213689
Belmont Hospital (BDH)	BDH	NG/enteral, malnutrition	GP referral required	49232298
Royal Newcastle Centre (RNC)	RNC	Malnutrition, rheumatology, dermatology and orthopaedics.	OP clinic referrals accepted from Consultants within RNC	Barbara Belavic 49223073
Centre for Psychotherapy	JFH Grounds	Eating disorders	GP referrals accepted. Referrals from specialists within the Centre for Psychotherapy.	Anjanette Casey 49246820
Community Nutrition Unit	Eastlakes CHC, Toronto Polyclinic, Raymond Terrace CHC, Nelson Bay CHC, Port Stephens.	Weight loss and management, high cholesterol, gastroenterology, enteral nutrition, malnutrition, food intolerance/allergies, antenatal, palliative, cardio-pulmonary and other medical diseases.	Health professional referrals accepted through Referral Information Centre (RIC) 49257990.	Margaret Rush 49246100
Maitland Hospital	Maitland Hospital (TMH)	Gestational diabetes and Paediatrics.	Appointments through HADS, need Obstetrician referral. Paeds: All referrals accepted	Donna Pearce 49392254

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Cessnock District Hospital	Cessnock District Hospital (CDH)	General outpatient clinic for weight management, cholesterol, gastroenterology and neurological. Home nutrition support clinic operates weekly. Diabetes clinics and Food for Thought program also available.	Referrals accepted by phone from GP's/medical specialists, clients and carers and all health professionals. Diabetes clinics referrals through HADS.	49910425
Lower Hunter Community Health	East Maitland CHC	Malnutrition, nutrition support	All referrals by phone and specified intake hours. LH CHC intake 49312003	Sharon Lawrence 49213000
Singleton Health Service	Singleton CHC	Nutrition support, Renal failure, Diabetes, weight control, Gastroenterology	Referrals for OP clinics accepted from all Health professionals and clients through Central Intake. Referrals for Diabetes information accepted through Singleton CHC.	Renae Hamilton 65719248 Central Intake Ph: 4931 2003 Fax: 4931 2005 Singleton CHC 6571 9248
Upper Hunter Health Service	Muswellbrook CHC	Urgent cases, nutrition support, diabetes, weight management	Referrals from General Practitioners, HNE Health staff.	Shaun Seldon 65422712
Cardiopulmonary Rehab Program	Newcastle East CHC	Cardiovascular and respiratory disease.	All referrals accepted for cardiac clients. Clients with respiratory disease require referral/involvement with a respiratory physician.	40164685

Occupational Therapy: Adult Outpatient Services

Service name	Location	Clinical Priorities	Referral Process	Contact Details
PADP	Wallsend Campus	Assessment and recommendation for the provision of equipment for all diagnostic groups.	Written and phone referrals accepted from all health professionals, carers, clients, community groups and NGO's.	Anneke Redman 49246251
Royal Newcastle Centre	RNC	Elective orthopaedic, rheumatology, hand clinic, ortho and medical rehab.	Referrals accepted from all agencies, GPs, carers, medical specialists, health professionals	Rosalie Bell 49223058
Rankin Park Day Hospital	Rankin Park Unit JHH Campus	Stroke, arthritic conditions, musculoskeletal, neurological, falls clinic and Parkinson's disease program.	Phone referral. All agencies, GP's, medical specialists and health professionals.	49855750
Belmont District Hospital	BDH	Outpatient services for non-complex equipment prescription, home assessment, assessment and management of non-complex hand conditions e.g. carpal tunnel syndrome, arthritis.	Written GP referrals accepted.	OT Team Leader 49232256
Calvary Mater Hospital	Calvary Mater Mercy Hospice	Oncology and haematology outpatient service. Palliative care outpatient service.	Phone referrals. Clients, GPs, Health professionals.	Andrew Wakely 49211250 Jenny Gleeson 49211922

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Newcastle Community Health Service	Newcastle East and West CHC, Toronto polyclinic, Raymond Terrace, Eastlakes CHC and Nelson Bay CHC	Home Modification Service Palliative Care Port Stephens (Nelson Bay, Raymond Terrace) offer general OT services.	Health professional referrals accepted through RIC.	RIC 49257990.
John Hunter Hospital	JHH	Limited outpatient service to renal, plastics, cardiac, HIV/Immunology and obstetrics. Outpatient rehab groups for cardiac (medical and surgical) and respiratory patients.	Written referrals preferred for renal and plastics outpatients. NGO's and GP referrals accepted for HIV clients only.	Maryanne Barlas 49223040
Singleton	Singleton CHC	Community Home Visits (HV) for equipment and home modifications for frail aged clients and disability.	All referrals by phone and specified intake hours. LH CHC intake 49312003	65719248
Cessnock District Hospital	CDH	Community HVs; OP - splinting and rehab.	Phone referrals accepted from all agencies and Health professionals with client's consent.	49910446
Kurri Kurri District Hospital (KKDH)	KKDH	Community HVs; OP - splinting and rehab.	Phone referrals accepted from all agencies and Health professionals with client's consent.	49363218
Upper Hunter Community Health	Muswellbrook CHC	Community HV OP splinting. Services to frail aged clients and disability not eligible for DADHC.	Phone referrals accepted from clients, GP's/Medical specialists, health professionals, agencies and NGO's.	65422070

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Newcastle Community Acute Post Acute Care (CAPAC)	Newcastle East CHC	Supported discharge from hospital. Short-term intervention including discharge home visits, minor modifications, equipment and functional assessments.	Medical specialists and health professionals from within the hospital prior to discharge.	Speed Dial 67912
Maitland Post Acute Community Care	Maitland Hospital	Early discharge from acute hospital and supported discharge from emergency. Home assessment for high-risk mobility/falls.	GP/ medical referrals as well as hospital health professionals and other Community services.	Tina Thomas 49392324
Spinal Cord Injury Service	Newcastle East CHC	Outpatient, outreach and consultative services for traumatic spinal cord injury for Southern and Taree HNEAHS.	Phone referrals accepted from all GPs/Medical specialists, health professionals, agencies, NGO's and carers.	49257888
Cardiopulmonary Rehab Program	Newcastle East CHC	Cardiovascular and respiratory disease.	All referrals accepted for cardiac clients. Clients with respiratory disease require referral/involvement with a respiratory physician.	40164685

Physiotherapy: Adult Outpatient Services

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Royal Newcastle Centre	RNC	Musculoskeletal and fracture clinic. Post-op elective orthopaedic surgery.	GP/medical specialist and health professional referral accepted.	49223079
Calvary Mater	Mater	Haematology and oncology.	Written referrals accepted from GP's, Medical Specialists and other Health professionals	Judy Holland 49211205 Fax 49211377
	Mercy Hospice	Palliative Care	Referral only accepted from palliative care service.	49211928
Toronto Polyclinic	Westlakes CHC	Orthopaedic and neurological	All referrals via RIC.	RIC 49257990
Belmont Hospital	BDH	All diagnostic groups except burns and hand therapy.	GP/medical referral required.	Peter Brown 49232019
Newcastle Community Health	Newcastle East/West CHC Newcastle, Eastlakes CHC.	Home visit physiotherapy services to housebound/disabled clients.	All referrals via RIC	RIC 49257990
Port Stephens Community Health	Nelson Bay CHC Raymond Terrace CHC	Musculo-skeletal, orthopaedics, neurological, cardiac rehab, respiratory and equipment hire. General Physiotherapy services.	All referrals via RIC	RIC 49257990

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Newcastle Community Acute Post Acute Care (CAPAC)	Newcastle East CHC	Supported discharge from hospital. Short-term intervention including discharge home visits, mobility reviews, home assessments and exercise programs.	Medical specialists and health professionals from within the hospital prior to discharge.	Speed Dial 67912
Cardiopulmonary Rehab Program	Newcastle East CHC	Cardiovascular and respiratory disease.	All referrals accepted for cardiac clients. Clients with respiratory disease require referral/involvement with a respiratory physician.	40164685
Maitland Hospital	TMH	All diagnostic groups except specialised caseloads such as lymphoedema.	GP/medical or Allied Health Professional referral. Client referrals not accepted.	Bronwyn Caldwell 49392219
Maitland Post Acute Community Care	TMH	Early discharge from acute hospital and supported discharge from emergency. Home assessment for high-risk mobility/falls.	GP/ medical referrals as well as hospital health professionals and other Community services.	Kathie Maloney 49392324
Kurri Kurri District Hospital	KKDH	All diagnostic groups	Referrals accepted from all Health Professionals.	Janelle Lymbery 49363249
Cessnock District Hospital	CDH	All diagnostic groups except specialised caseloads such as lymphoedema.	GP/ medical or Allied Health Professional referral.	Adrian Simmons 49910597

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Singleton District Hospital (SDH)	SDH	Limited general physiotherapy services available	GP/medical referral required.	Kathie Maloney 6572324
Dungog Community Hospital	Dungog	Limited general physiotherapy services available.	GP/medical referral required.	Margaret Clithero 49957000
Upper Hunter Community Health	Muswellbrook CHC	General physiotherapy, cardiac rehab, health promotion and Lymphoedema Management.	Referrals from GP/medical and other health professionals accepted	Muswellbrook/Denman 65422031 Scone 65402157 Merriwa 65482006 Murrurundi 65466106

Social Work: Adult Outpatient Services

Service name	Location	Clinical Priorities	Referral Process	Contact Details
John Hunter Hospital	JHH	Emergency Department Service: Sudden Death and child protection	Triage through ED	49213000
John Hunter Hospital	JHH	Outreach clinics for Hep C, HIV, Renal, Post Natal Depression and High Risk Obstetric patients and Chronic Disease management.	Via treatment program through Division of Medicine. Obstetrics through ANC, Maternal home visiting services and DOCS	49213700
Calvary Mater	Mater	Social work services for oncology and haematology clients and families.	GP/medical specialists, health professionals, clients and carers and all agencies.	49211298
Royal Newcastle Centre	RNC	Primarily inpatient service to Rheumatology, Ophthalmology and elective orthopaedics.	Phone or fax referrals accepted.	49223080 Fax: 49223041
Belmont Hospital	BDH	Emergency Department Service for domestic violence, child protection and trauma.	Triage through ED.	49232103
Cessnock Community Health	Cessnock CHC Kurri Kurri CHC	All diagnostic groups Young Parents Network	All referrals by phone and specified intake hours. LH CHC intake 49312003 Young parents and parents to be up to age 25.	Belinda Latimore 49910423 Jessica Grant 49910588

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Singleton Community Health	Singleton CHC	All diagnostic groups	All referrals by phone and specified intake hours. LH CHC intake 49312003	Melissa Davis 65719248
Maitland Hospital	TMH	All diagnostic groups for counselling, assessment, individual and group therapy.	Phone referrals accepted from all health professionals, clients, cares and agencies.	Helen Townsend 49392342
Newcastle Community Health Service	CHC's in Newcastle, Nelson Bay, Raymond Terrace, Toronto, Wallsend and Windale.	Child protection, suicidality, domestic violence and recent trauma.	All referrals via the Referral information Centre (RIC) 49257 990	Christopher Hart 49246100
Upper Hunter Community Health	Muswellbrook CHC	General community Health Social Work service. Counselling for individuals, couples, families and groups.	Referral accepted via phone.	Sue Gould 65422083
Lower Hunter Community Health	East Maitland CHC Dungog CHC	All diagnostic groups	All referrals by phone and specified intake hours. LH CHC intake 49312003	Kathryn Bennett 49312000
	Family Care Cottage	Postnatal stress, anxiety, Parenting Issues with babies and young children, Family of origin issues, birthing experiences.	All referrals by phone	Chris Harle 49 392530

Speech Pathology: Adult Outpatient Services

Service name	Location	Clinical Priorities	Referral Process	Contact Details
John Hunter Hospital	JHH	Specialised services for dysphagia, MBS, communication disorders, voice, ENT, chronic cough/VCD.	GP/medical specialist referral required for Dysphagia and MBS. Referrals accepted from all Health professionals, clients, carers and agencies.	49213700 Fax: 49845560
Belmont District Hospital	BDH	Dysphagia, communication disorders and voice.	GP/medical specialist referral required for Dysphagia. Referrals accepted from all Health professionals, clients, carers and agencies.	49232019
Calvary Mater	Mater	Limited outpatient service for dysphagia and communication.	Referrals accepted from radiotherapy clinics and health professionals involved with the client. Other outpatient referrals accepted if appropriate.	Tricia Potter 49211162
Maitland Hospital	TMH	Dysphagia, communication disorders, voice. Individual and group therapy available.	Clients, GPs, Medical and Health Professionals, Speech pathologists, Nursing Homes, ACAT. Phone referral.	Nik Byrne 49392249
Upper Hunter Cluster	Muswellbrook CHC	Dysphagia, communication disorders and voice.	Referrals accepted from GP/medical specialist, clients/carers, all health professionals and agencies.	65422085

Service name	Location	Clinical Priorities	Referral Process	Contact Details
Lower Hunter Cluster	CDH and KKDH	Dysphagia and communication disorders.	Referrals by phone direct to the department.	Anita Bomann-King 4991 0514
Community Health	CHC's in Newcastle, Nelson Bay, Raymond Terrace, Toronto, Wallsend and Windale.	Assessment and management of generalised caseload.	All referrals via RIC	RIC 49257990