

---

Funded by Continuing Care and Clinical Service Development Section, Programs Branch  
Metropolitan Health and Aged Care Services  
Department of Human Services  
Victoria

## Report

# Transfer of Young Adults with Complex Medical Needs Project

Prepared by Felicity Sloman, Transition Project Officer,  
Royal Children's Hospital  
June 2005

### Definitions

**'Transition'** is the planned move of young people from paediatric health care providers to adult providers/services. To be successful and ensure a quality continuum of care, transition should be well coordinated and well planned.

The **'transfer'** of medical care should only be considered as one component of the transition process. Consideration also needs to be given to other areas such as; psychosocial, vocational and educational needs.

## Table of Contents

---

		<b>Page No.</b>
<b>1.</b>	<b>Acknowledgements</b>	3
<b>2.</b>	<b>Executive Summary</b>	4
<b>3.</b>	<b>Introduction</b>	7
<b>4.</b>	<b>Background</b>	8
<b>5.</b>	<b>Transition Project</b>	10
4.1	Aims	10
4.2	Scope	10
4.3	Methodology	11
4.4	Outcomes	16
<b>6.</b>	<b>Discussion/Recommendations</b>	18
5.1	General	18
5.2	Clinic design and approach	20
5.3	Transition policy and process RCH	21
5.4	Information sharing	21
5.5	General learnings from the project	21
<b>7.</b>	<b>Summary of Recommendations</b>	23
<b>8.</b>	<b>Conclusion</b>	24
<b>9.</b>	<b>Bibliography</b>	25
<b>10.</b>	<b>Appendices</b>	26
Appendix 1	Working Party & Executive Sponsors	26
Appendix 2	Project Officer Position Description	28
Appendix 3	List of consultations	30
Appendix 4	Transfer summary record	31
Appendix 5	Transition pathway	33
Appendix 6	Principles of transition	35
Appendix 7	Flowchart of multidisciplinary clinic	36
Appendix 8	List of references	37
Appendix 9	Education Session Programs	47

### Abbreviations

Royal Children's Hospital	RCH
Child Development and Rehabilitation	CDR
Royal Melbourne Hospital, (Royal Park Campus)	RMH
St Vincent's Hospital	SVH
Monash Medical Centre, Clayton	MMC
Sub-acute Ambulatory Care Services	SACS
Department of Human Services	DHS

## **1. Acknowledgements**

---

This project could not have been undertaken without the commitment and support of the Working Party and Executive Sponsors who were generous with their time and expertise.

Dr Christine Kilpatrick at Melbourne Health, Dr Peter Hunter at St Vincent's Health, Mr Allan Lilley at Southern Health and Ms Louise Devereux at the Royal Children's Hospital supported the project as Executive Sponsors.

On the Working Party, Ms Chris Blackburn and Dr Barry Rawicki from Southern Health brought the project a wealth of practical experience and the benefit of many years' expertise working with the target patient groups. Dr Geoff Abbott at Melbourne Health, Dr Genevieve Kennedy at St Vincent's Health, Dr Dinah Reddihough and Ms Louise Devereux at the Royal Children's Hospital provided leadership and energy as new services and ways of working were established.

Thank you to all clinicians and allied health professionals participating in the project who have been most supportive and open to altering their work practices to improve transition processes for the client groups involved.

Finally, thank you to the young people and their families for placing in us, their trust and participating in the process to improve transition programs for complex and disabled young adults and their continuing health care in the adult world.

This project was strongly supported and funded by the Continuing Care and Clinical Service Development Section, Programs Branch, Metropolitan Health and Aged Care Services, Department of Human Services, Victoria.

---

## 2. Executive Summary

---

To date, in Victoria, many young adults with complex disabilities have continued to receive their health care at the Royal Children's Hospital (RCH) beyond the point at which it would be appropriate for them to access adult hospital services. In large part this has been because multidisciplinary, client-centred ambulatory services specifically targeted at their needs have not developed in the adult sector in all areas of the state of Victoria. The practical upshot of this situation is that an unsustainable number of overage patients currently continue to receive coordinated care through the RCH, which cannot provide an appropriate setting for caring for adults. At the same time it is apparent that there are also many young adults in the community who have theoretically been transferred to adult health care providers, but who have in fact dropped out of the system and are not receiving appropriate medical care.

The 2002 *Review of Victorian Paediatric Services* characterised the overall situation as unsatisfactory, and described many young adults as being in a "limbo situation." The Review recommended that the needs and issues related to transitioning these patient groups be identified, and that appropriate programs be developed. In its *Response* (October 2003) the Department of Human Services agreed to examine transition needs in Victoria in consultation with providers and individuals with expertise and experience with the issues, and to develop two pilots.

This report relates to the project auspiced by the Continuing Care and Clinical Service Development Section of Programs Branch, which has had a focus on developing sustainable transition processes for two specific patient groups, including the development of new sub-acute ambulatory care services (SACS) and service models in the adult sector. Within RCH, this project has been undertaken within the context of a much wider focus on transition planning.

The aim of the project was to achieve the successful transition of a total of 15-20 young adults with complex medical needs resulting from cerebral palsy and spina bifida from the RCH to participating Health Services. This was to involve:

- Establishing clinics and piloting clinic models for the target patient groups at St Vincent's Hospital (SVH) and the Royal Melbourne Hospital (RMH);
- Actively overseeing the transfer of patients to SVH and the RMH, ensuring the provision of health care was uninterrupted, coordinated, developmentally appropriate and psychologically sound;
- Ensuring the needs and expectations of the young person, family and the health team were met;
- Developing processes, protocols and relationships that would facilitate the routine transition of such patients from the RCH to the adult system across the state; and
- Informing the development of Departmental policy regarding transition issues and service models for sub-acute services, as well as other key Departmental policy areas.

After a period of preliminary consultation and planning, the project was conducted over eight months, from November 2004 to June 2005. It was conceptualised as a piloting exercise, to develop transition processes and service models, which, if successful, could be sustainably mainstreamed. Participating patients came from two patient groups, being young adults with complex medical needs due to either spina bifida or cerebral palsy. The involvement of clinicians who participated in the Chronic Neurology clinic at Monash Medical Centre (MMC) was understood as crucial to the project. This clinic had been developed by committed clinicians in response to the patient need, despite many structural barriers. While it was not established within the SACS Framework, it had developed an excellent clinical model for providing integrated sub-acute ambulatory care for the target patient groups, and clinicians were able to bring a wealth of expertise and experience to the project.

While four hospitals participated - the RCH, MMC, SVH and the RMH Royal Park Campus - the project focussed on developing SACS at two sites. SVH and the RMH each developed a

multidisciplinary clinic – within the “specialist clinic” framework already existing in the SACS sector – to provide clinical assessment and management, as well as appropriate referrals both within the Health Service and to community-based services. SVH developed a clinic for people with cerebral palsy, and the RMH a clinic for people with spina bifida. MMC clinicians brought clinical experience and practical expertise in providing services for the target patient groups to the project, acting as a key resource for the new services. While the focus was on providing appropriate transition for RCH patients, it was acknowledged that the clinics would ultimately both provide ongoing services for people with spina bifida and cerebral palsy, and accept self-referrals and referrals from other community providers.

A working party consisting of clinical leaders at participating sites and Departmental representatives was formed to oversee the project (see Appendix 1 for the Working Party’s Terms of Reference and membership), and a 0.5 EFT Project Officer, based at the RCH, was appointed to manage the project (see Appendix 2 for the Project Officer’s position description).

A literature survey, information sharing with similar projects in other jurisdictions, and consultations with consumer and community groups, as well as input from clinicians involved with the specialist neurological clinic at MMC, provided an evidence base for the development of new services and transition processes. After consultation with the relevant departments within the RCH, SVH and the RMH, experienced clinicians were appointed to a part-time coordinator role at each site. This also brought the clinic model in line with the coordination model used in other SACS specialist assessment and management services.

Clinic Coordinators took on similar roles at each site, encompassing responsibility for clinic bookings, room set-up, creation and retrieval of unit records and relevant paperwork from referrers, liaison with RCH staff and other service providers, liaison with patient and carers, follow-up on clinic action plan – including appropriate referrals and documentation, data collection and liaison roles.

Clinical leaders at SVH and the RMH, assisted by the Project Officer, identified and involved the clinicians at each site who would be involved in the clinic. They also identified and liaised with key specialty areas within their Health Service to which clinic patients would frequently be referred.

Prior to the establishment of the new clinics, clinicians from the RCH, SVH and the RMH were invited to participate in clinics at MMC, and clinicians from the RMH attended the paediatric spina bifida clinic at the RCH. Information sharing and case presentation sessions also brought together clinical teams from the RCH and the adult sites. These sessions were used to provide a clinical orientation to working with the patient groups in general and to gain a shared understanding of the histories and future needs of the transferring patients.

The Project Officer developed a standard transfer template, and worked with clinicians at all sites to identify patients who would transfer from the RCH to the participating adult sites as part of the project. She worked with patients and families, and supported medical staff, to ensure that patients were prepared for the transfer. Between one and three transferring patients were seen at each clinic session. After each clinic session, the Clinic Coordinator and members of the team reviewed learnings from the session and built these into planning for the next.

The key outcomes of the project were:

- 11 young adults with spina bifida or cerebral palsy were transferred from the RCH to SVH and the RMH.
- Sustainable clinics with an appropriate model of care were developed at SVH and the RMH.
- Transition processes and protocols were developed and used to enhance practice, relationships between the RCH and the participating hospitals were established, and a process for establishing new clinics was documented.

- Regular reports were provided to the Department of Human Services, and project information was used to inform a successful budget submission for growth in SACS funding in 2005-06.

A summary of the recommendations for practice and further work arising from the project can be found in Section 7 of this report.

### **3. Introduction**

---

To date, in Victoria, many young adults with complex disabilities have continued to receive their health care at the Royal Children's Hospital (RCH) beyond the point at which it would be appropriate for them to access adult hospital services. It has been difficult to transfer them to adult services in some parts of Melbourne because many facilities have not been able to provide the specific sorts of services that this group of patients with complex, specialised needs requires.

This project was initiated in order to develop approaches and services which will enable young adults with complex health needs to achieve an appropriate transition from paediatric to adult health care, moving from the RCH to multidisciplinary, client-centred adult services designed to meet their needs.

This report includes detailed information on the project, including its aims and scope. It documents the methodology used to create successful transition experiences for patients and establish services for them in the adult sector, with a focus on the development of specialist sub-acute ambulatory care clinics.

It discusses project outcomes and achievements, as well as identifying barriers and makes recommendations for:

- Successful transition practice for the target patient groups;
- Appropriately meeting the medical needs of these patient groups in the adult health care sector; and
- Ongoing project work.

#### 4. Background

---

A growing number of young people with developmental disabilities and/or other complex medical needs are surviving to young adulthood and beyond, partly as a result of significant advances in medical science, practices and technologies. As a result, an increasing number of young people with complex medical needs need to transition from the paediatric to the adult health care service system.

There is now a strong body of literature on transition from paediatric to adult health care both internationally and within Australia. It is increasingly understood to be an essential aspect of paediatric practice and is considered a major milestone in the life of most young people and their families. A successful transition for a young adult involves considerably more than just the formal transfer processes. Many patients and their families experience fear and uncertainty about the prospect of their future health care in the adult system. Paediatric staff need to devote time and resources to preparing patients adequately – and positively – for the systemic differences in the way paediatric and adult health care is provided.

If well-planned transition processes are not created, young people are likely to experience an ad hoc, ill-prepared transfer to adult care. The consequence of this is an increase in the rate of young people dropping out of the health care system soon after the transfer to adult care, often not re-entering the system until they require emergency intervention. Many preventable exacerbations of their condition could be avoided by regular review with appropriate and timely intervention.

While there is thus a need to focus on transition processes themselves, there is also a need to ensure that appropriate services exist for young adults with complex needs to transfer to. Many young adults with developmental disabilities have a complex matrix of medical and social needs. They require a range of health and social services, often involving many different organisations. While many individuals may often need to use acute and emergency services, access to multidisciplinary assessment and therapy services for ongoing maintenance and care is critical. The sub-acute ambulatory care sector is therefore the most appropriate for the provision of longer term medical care, as it is best able to address the multi-faceted health requirements of this group of young people through its more holistic focus and multidisciplinary approach to patient care. However, while Victoria has a well-developed sub-acute ambulatory care sector, encompassing centre-based and home-based rehabilitation services and a range of specialist assessment and management services, historically these services have tended to be more focussed on providing care for older people, and most have had minimal experience in working with young adult patient groups.

The need for services for young people with developmental disabilities to be provided in adult facilities was first identified by the Department of Child Development and Rehabilitation (CDR) in the RCH, in 1983. Such services often did not exist, especially for patient groups who had not previously been expected to survive childhood. The RCH has, wherever possible, taken the opportunity to work with the adult sector to help build these services.

Despite this, funding and organisational structures, combined with the lack of a statewide policy framework, have often created barriers to the success or the sustainability of these efforts. For example, in 1983 a program was established whereby registrars training in rehabilitation medicine spent a period of two weeks in the CDR Department, to educate them about the patient groups and their health needs. This program lapsed a few years later when funding was inadequate to sustain it. In 1994, there was a joint project with the Austin Hospital, which resulted in the transfer of a group of patients with spina bifida, but there were difficulties in the transfer of further patients.

Even where appropriate adult sector services have been developed and maintained through committed clinical leadership, their geographical location has often meant that they are not easily accessible to all the patients who need them. For example, for young adults with a range of complex neurological needs, excellent transition and ongoing health care services have been available in southern metropolitan Melbourne at MMC. However, access to

appropriate adult health care had been more problematic for similar patients living in the northern and western areas of Melbourne and some country areas.

The practical upshot of this situation is that an unsustainable number of overage patients currently continue to receive coordinated care through the RCH, which cannot provide an appropriate setting for caring for adults. These patients require multidisciplinary care and may see a variety of clinicians depending on their needs. They may utilise a variety of other RCH services, including the equipment distribution centre, orthotic and prosthetic services, stomal therapy, and radiology. In general, the contact each of these patients has with the RCH is regular but of varying frequency. For example, some may need to access service more than once a month while for others it might be once every six months. At the same time it is apparent that there are also many young adults in the community who have theoretically been transferred to adult health care providers, but who have in fact dropped out of the system and are not receiving appropriate medical care.

The 2002 *Review of Victorian Paediatric Services* characterised the overall situation as unsatisfactory, and described many young adults as being in a "limbo situation." The Review recommended that the needs and issues related to transitioning these patient groups be identified, and that appropriate programs be developed. In its *Response* (October 2003) the Department of Human Services agreed to examine transition needs in Victoria in consultation with providers and individuals with expertise and experience with the issues, and to develop two pilots.

During 2004, the Department engaged in discussions with both paediatric and adult service providers, and it was decided to progress two "Transition" Projects. This report relates to the project auspiced by the Continuing Care and Clinical Service Development Section of Programs Branch, which has had a focus on developing sustainable transition processes for two specific patient groups, including the development of new sub-acute ambulatory care service models in the adult sector. However, close links have been maintained throughout with the other project (auspiced by the Access and Metropolitan Performance Branch), which has had a more general focus on paediatric transition issues. These links have taken the form of collaborative work within the Department, and also the appointment of a joint Project Officer based at the RCH. Further detail about the project scope and structure is provided in Section 5.3, Project Methodology.

At the RCH, this project has been undertaken within the context of a much wider focus on transition planning, and a formal policy on transition was introduced to the hospital in October 2004.

## **5. Transition Project**

---

### **5.1 Project Aims**

The aim of the project was to achieve the successful transition of a total of 15-20 young adults with complex medical needs resulting from cerebral palsy and spina bifida from the RCH to participating Health Services. This was to involve:

- Establishing clinics and piloting clinic models for the target patient groups at SVH and the Royal Melbourne Hospital RMH;
- Actively overseeing the transfer of patients to SVH and the RMH, ensuring the provision of health care was uninterrupted, coordinated, developmentally appropriate and psychologically sound;
- Ensuring the needs and expectations of the young person, family and the health team were met;
- Developing processes, protocols and relationships that would facilitate the routine transition of such patients from RCH to the adult system across the state; and
- Informing the development of Departmental policy regarding transition issues and service models for sub-acute services, as well as other key Departmental policy areas.

### **5.2 Project Scope**

After a period of preliminary consultation and planning, the project was conducted over eight months, from November 2004 to June 2005.

Participating patients came from two patient groups, being young adults with complex medical needs due to either spina bifida or cerebral palsy.

Despite the large number of young adult patients in these groups still attending the RCH, it was expected that only a limited number of patients (15-20 was initially envisaged) would be transferred from the RCH to adult services as part of the project.

The project was conceptualised as a piloting exercise, to develop transition processes and service models, which, if successful, could be sustainably mainstreamed.

Four hospitals participated in the project: the RCH, the MMC, SVH and RMH (Royal Park Campus). Initially the Bendigo Health Care Group (BHCG) was also involved. However, Bendigo withdrew from the project, as it was unable to proceed with clinic development in 2004-05 due to temporary capacity issues.

The project focused on developing sub-acute ambulatory care services (SACS) – particularly within the “specialist clinic” model already existing in the SACS sector – to meet the health needs of the target patient groups at SVH and RMH. In addition, the development of appropriate linkages with relevant acute and community-based services was considered to be part of the scope of the project.

Because a multidisciplinary clinic providing assessment, care and referral for these patient groups already existed at MMC, clinicians from Southern Health were crucial participants in the project. They brought clinical experience and practical expertise in providing services for the target patient groups to the project, acting as a key resource for clinicians developing new services.

The project also considered the relationship between RCH and the adult service system generally, so that learnings from the project could inform the mainstreaming of the pilot services, and the development of future pilots and Department policy.

## 5.3 Project Methodology

### 5.3.1 Initial consultation and discussion

In the context of responding to the recommendations of the *Review of Victorian Paediatric Services* (December 2002), a series of discussions and consultations were held between several units within the Department of Human Services, the RCH and other service providers including Southern Health during 2003 and 2004. These established a better understanding within the Department of both gaps in the current service system leading to transition difficulties, and of existing services and models.

In April 2004, the RCH was invited to formally submit a project proposal to initiate transition for identified patient groups in geographical areas where appropriate adult services were not available for those groups.

Further discussion between the then Continuing Care Section (later restructured as the Continuing Care and Clinical Service Development Section) of the Department and senior clinical and executive staff from the RCH and adult Health Services in the relevant areas led to the refining of the target patient groups to the two with the largest number of overage patients still attending the RCH, patients with spina bifida and cerebral palsy. It was determined that MMC had an excellent clinical model for providing care for these target groups. It was also established that Melbourne Health, St Vincent's Health and BHCG:

- were appropriately located to provide services to patients unable to access the services provided by Southern Health at MMC in south-eastern Melbourne;
- were interested in developing services for the identified target groups; and
- had an appropriate mix of clinicians and configuration of services available to develop such services.

The Continuing Care and Clinical Service Development Section allocated project funds in 2004-05 to a project to pilot transition processes and develop appropriate services for young adults with spina bifida and cerebral palsy.

The service model to be developed at each site was to be based around the establishment of a multidisciplinary clinic that would provide clinical assessment and management for young adults with spina bifida and cerebral palsy, as well as appropriate referrals both within the Health Service and to community-based services. While the focus of the pilot project was on providing appropriate transition for RCH patients, it was acknowledged that the clinics would ultimately both provide ongoing services for people with spina bifida and cerebral palsy, and accept self-referrals and referrals from other community providers.

It was determined that each adult site would work with a different patient group, in order to take advantage of existing, and foster the development of new, specialist expertise. SVH developed a clinic for people with cerebral palsy, and the RMH a clinic for people with spina bifida.

### 5.3.2 Working Party

A Working Party was formed to refine the project brief, define the role of the Transition Project Officer, and oversee the pilot project. The Terms of Reference and Membership of the Working Party form Appendix 1.

The Working Party was chaired by the Manager, Health Independence Programs and composed of:

- senior rehabilitation physicians from the RCH, Melbourne Health, St Vincent's Health, Southern Health, and, until they withdrew from the project, the BHCG;
- the Unit Manager from RCH Adolescent Unit, and a senior physiotherapist from the MMC; and
- Department of Human Services (DHS) representatives from the Hospital Demand Management unit and the Disability Branch, as well as a project officer from the Continuing Care and Clinical Development Section to provide secretariat support.

The Working Party met every two months to consider progress to date, advise on ways to resolve any issues that had arisen, and plan in detail for ongoing work.

Each participating Health Service nominated an executive sponsor, to provide executive leadership and support for the project within their organisation.

### *5.3.3 Project Officer*

The Working Party developed a position description for a Transition Project Officer to be based at the RCH (refer to Appendix 2).

The Transition Project Officer position was internally advertised at participating Health Services, as a six month 0.5 EFT secondment opportunity. The preferred candidate in the selection process had a background in nursing in both paediatric and adult health care, and had been appointed to 0.5 EFT position with the other "Transition Project" funded through the DHS Hospital Demand Management unit through an independent selection process.

### *5.3.4 Evidence base*

The Project Officer ensured that transition processes and new models of adult care were developed in line with existing evidence. This included conducting a literature survey (and drawing on the bibliography assembled by the New South Wales (NSW) Transcare Project team, see references in Appendix 8). It also involved visiting and exchanging information with other states with working, evolving models for transition, namely NSW and Western Australia.

### *5.3.5 Consultation*

In the initial planning stages of the project, the Project Officer consulted with and involved relevant departments within the RCH, SVH and the RMH. Key consumer and community groups were also consulted at this stage. A full list of consultations is detailed in Appendix 3.

Discussions with experienced clinicians involved with the MMC specialist neurological clinic were also a crucial part of the planning stages.

### *5.3.6 Site Coordinators*

As a result of initial planning and consultation, it was determined that a coordinating role was required at each participating site. The Project Officer acted as Coordinator at the RCH, while experienced clinicians were appointed to part-time Clinic Coordinator roles at SVH and the RMH. This also brought the clinic model in line with the coordination model used in other SACS specialist assessment and management services.

SVH allocated 0.2 EFT immediately the project commenced. This Coordinator finished on 30 June 05 and a replacement Coordinator had not been appointed at the time of completion of this report (late August).

The RMH allocated 0.1 EFT during the pilot project and then increased this to 0.2 EFT during the second phase (after 1 July 2005). Due to staff turnover, there was a six week period where the Project Officer at RCH fulfilled the RMH coordinator role.

Clinic Coordinators took on similar roles at each site.

At the RMH the Clinic Coordinator was responsible for clinic bookings, room set-up, creation and retrieval of URs and relevant paperwork from referrers, liaison with RCH staff and other service providers, liaison with patients and carers, conducted pre clinic phone assessments, follow-up on clinic action plan – including appropriate referrals and documentation, data collection and clinic audit, liaison with SACS manager.

At SVH, the Clinic Coordinator was responsible for clinic bookings, room set-up, creation and retrieval of unit records and relevant paperwork from referrers, liaison with RCH staff and other service providers, liaison with patient and carers, follow-up on clinic action plan – including appropriate referrals and documentation, liaison with acute services during inpatient admissions, data collection and clinic audit, liaison with DHS, created budget for the pilot project, developed education package for staff unfamiliar with medical condition, provided clinical expertise during clinic.

### 5.3.7 Development of Clinic Model

Clinical leaders at SVH and the RMH, assisted by the Project Officer, identified and involved the clinicians at each site who would be involved in the clinic. They also identified and liaised with key specialty areas within their Health Service to which clinic patients would frequently be referred.

#### Key clinic personnel

St Vincent's Hospital	Royal Melbourne Hospital
Medical	Medical
Physiotherapy	Physiotherapy
Occupational Therapy	Occupational Therapy
Dietetics	Social Work
Social Work	

#### Other departments involved

St Vincent's Hospital	Royal Melbourne Hospital
Orthopaedics	Orthotics
Gastroenterology	Continence
Dual Disability Clinic (Intellectual Disability)	
Speech Therapy	

### 5.3.8 Site visits to MMC

Clinicians from the RCH, SVH and the RMH were invited to participate in clinics at MMC, to gain first hand experience of working with these patient groups.

Hospital	Date/Clinic
RCH	Frederichs Ataxia Clinic 23/11/04 Spina Bifida Clinic Dec 04
RMH	Spina Bifida Clinic Dec 04
SVH	Spina Bifida Clinic Dec 04
SVH	Meeting x 2 with RMH Clinic Coordinator

These visits provided an objective opportunity to see how a clinic could be conducted. It provided the participants with ideas on how they may run their own clinics and what disciplines would be required to participate in their clinics.

The staff from the RMH also attended the paediatric spina bifida clinic at the RCH to seek greater understanding of the environment these young adults are transferring from and the personnel involved in their care within the paediatric setting.

The two Clinic Coordinators at each site regularly shared resources and ideas to assist with the smooth running of their respective clinics.

Disability Services were requested on numerous occasions to present at each site on support packages to assist their clients however they have not been able to arrange a suitable time thus far.

### 5.3.9 *Interactive information sharing/education/case presentations*

The Project Officer organised and facilitated information sharing sessions that brought together clinical teams from the RCH and the adult sites. These sessions were used to provide a clinical orientation to working with the patient groups in general and to gain a shared understanding of the histories and future needs of the transferring patients.

These were held at the RMH on Tuesday 25 January 2005 and at SVH on Wednesday 2 February 2005 (see Appendix 9 for full program outlines).

On both occasions MMC staff attended and provided guidance and expertise.

### 5.3.10 *Preparation of transfer information*

The Project Officer consulted with the Working Party and clinicians from SVH and the RMH to determine the optimal content of referral letters for transferring patients, and any other information needs they had.

A standard transfer template was developed (refer to Appendix 4) and the Project Officer worked with RCH clinicians and Departments to enable its use in the pilot project.

### 5.3.11 *Identification and involvement of transferring patients*

The Project Officer worked with clinicians at all sites to identify patients who would transfer from the RCH to the participating adult sites as part of the project. The Project Officer then consulted patients and their families about their needs and expectations regarding the transfer and clinic visits. As clinic dates approached, she worked with patients and families to ensure that they were prepared for transfer, and for dealing with the practicalities of attending a new health care provider. In order to promote sustainability of the project the Project Officer supported the medical staff to ensure that patients were prepared for the transfer. Often the Project Officer would be present at the final outpatients appointment to assist with any questions about the new adult clinic they would be attending.

### 5.3.12 *Clinic sessions*

#### *Clinic dates*

<b>Royal Melbourne Hospital</b>	<b>St Vincent's Hospital</b>
27/4/05 x 1 patient	9/3/05 x 2 patients
25/5/05 x 2 patients	6/4/05 x 2 patients
22/6/05 x 1 patient	1/6/05 x 1 patient (2 cancelled)
24/8/05 x 1 patient	Clinic Coordinator contract finished and no further clinics held as yet.

For administrative and staffing-related reasons, the clinics have taken time to commence as well as maintain momentum. The St Vincent's clinic has now a significant waiting list and will recommence as soon as new staff have taken up their new positions.

### 5.3.13 Clinic evolution

#### *St Vincent's Clinic*

This clinic commenced very quickly as the Clinic Coordinator was able to be appointed almost immediately. She developed documentation for the clinic, booked the room and organised the patients with the Project Officer at the RCH. Transfer summary records were prepared swiftly by the paediatricians and apart from two complex patients cancelling at the last minute the clinic ran very smoothly. Unfortunately the contract for the Clinic Coordinator finished at the end of June and she departed on pre arranged leave. There have been administrative delays in employing new staff.

Between 1-3 new patients were booked at each monthly clinic. Medical, physiotherapy and occupational therapy staff met the patient and family at the first consultation in a large room. The consultation was informally led by medical staff initially and then a physical examination was undertaken with physiotherapy and occupational therapy interviewing family and patient as required. After this was completed (approximately 40 minutes duration) the patient would see a Dietitian if needed and be linked in to the St Vincent's Home Enteral Nutrition (HEN) program. It was important not to cease the HEN program at the RCH until established at the new hospital. This was a point of great anxiety for families and liaison with RCH Dietetics was essential to ensure they helped to allay anxiety and reassure patients that they would not be denied formula, essential for their child.

Further plans for external referrals were made at this stage or appointment for review made. The Clinic Coordinator followed up outstanding issues, for example with the Royal District Nursing Service, after the clinic was completed.

#### *Royal Melbourne Hospital - Royal Park Campus*

This clinic was slower to establish due to administrative delays and human resource barriers. Once commenced 1-2 patients were seen at each monthly clinic. There were difficulties obtaining timely transfer summary records from paediatricians and establishing a sustainable, simple process is still proving to be a challenge. This was due in part to heavy workloads of part time staff but also lack of prioritising in preparing transfer information. However, this has provided excellent opportunities for further education to take place at the clinic and two additional education sessions have been held. A paediatrician from the RCH Spina Bifida clinic and the Clinic Coordinator at the MMC's adult spina bifida clinic met with the clinic staff to provide guidance and support.

### 5.3.14 Review and follow up

After each clinic session, the Clinic Coordinator and members of the team reviewed learnings from the session and built these into planning for the next. The Coordinator provided patient follow-up, progressed external referrals, liaised within the Health Service for internal referrals, and liaised with family. The Coordinator also fed back any more general issues to the Project Officer.

The Project Officer reported on progress to the Working Party at meetings, and maintained contact with Working Party members and DHS as appropriate between meetings. The Chair of the Working Party regularly reported on progress at Paediatric Rehabilitation Reference Group meetings, to ensure that transition issues were canvassed in this forum.

## 5.4 Outcomes

Aim	Outcome
<p>Achieve the successful transition of a total of 15-20 young adults with complex medical needs and/or developmental disabilities from the RCH to participating Health Services.</p>	<p>11 young adult patients were transferred in total from the RCH to St Vincent's Health and Melbourne Health.</p> <ul style="list-style-type: none"> <li>○ 6 patients with Cerebral Palsy to St Vincent's Health</li> <li>○ 5 patients with Spina bifida to Melbourne Health</li> </ul> <p>Extensive consultations and education within the RCH led to support for the project and increased awareness of the importance of transition, including use of transition protocols and project materials for target patient groups.</p> <p>RCH CDR staff provided training and case presentations for adult sector clinicians, and continue to do so.</p> <p>Transition documentation developed and made available on the web.</p>
<p>Actively overseeing the transfer of patients to SVH and the RMH, ensuring the provision of health care was uninterrupted, coordinated, developmentally appropriate and psychologically sound.</p>	<p>Sustainable clinics with an appropriate model of care were developed at SVH and the RMH.</p> <p>Lead clinicians at SVH and the RMH Royal Park Campus identified key team members and departments in their organisations; coordinated participation and input from medical and allied health staff; provided leadership and guidance; liaised with executive staff and other internal management; liaised with the Department of Human Services through membership of the Working Party.</p> <p>Senior clinicians from MMC provided a core of practical and pragmatic expertise that was made available to the project in all settings, including secondary consultation for specific clients.</p> <p>Clinic Coordinators appointed.</p> <p>Education sessions, case presentations and cross-site visits held.</p> <p>All sites shared documentation and clinical expertise to enable effective work with patients being transferred.</p> <p>Executive-level meetings convened where support necessary for planning and implementation.</p> <p>Collaborative work between all Health Services ensured high quality care.</p> <p>Feedback from patients and families generally indicated satisfaction with the transition experience.</p>
<p>Develop processes, protocols and relationships that will facilitate the routine transition of such patients from the RCH to the adult system across the state.</p>	<p>Transition processes and protocols were developed and used to enhance practice, relationships between the RCH and the participating hospitals were established, and a process for establishing new clinics was documented.</p> <p>Processes:</p> <ul style="list-style-type: none"> <li>○ Increased awareness of RCH transition policy by meetings, presentations, Grand Rounds session, etc.</li> <li>○ Developed flowchart indicating stages of developing</li> </ul>

Aim	Outcome
	<p>clinics.</p> <p>Protocols: Materials developed, approved and made available on RCH intranet including:</p> <ul style="list-style-type: none"> <li>○ Transfer record template</li> <li>○ Family information resources</li> <li>○ Post-transfer patient and carer questionnaires</li> <li>○ Other resources for clinicians</li> </ul> <p>Relationships:</p> <ul style="list-style-type: none"> <li>○ Key RCH internal stakeholders identified and engaged.</li> <li>○ Relationships built with relevant departments and clinicians at Southern, St Vincent's and Melbourne Health.</li> <li>○ Facilitated where appropriate the development of relationships between internal stakeholders in adult sector clinics.</li> <li>○ Identified, met and shared resources with interstate and overseas transition practitioners.</li> <li>○ Created an email mailing group for Australian transition project workers.</li> </ul> <p>Dialogue between project participants is ongoing and relationships are being further developed.</p>
<p>Inform the development of Departmental policy regarding transition issues and service models for sub-acute services, and inform other key Departmental policy areas</p>	<p>Regular reports provided to Working Party and DHS staff.</p> <p>Regular reports on progress provided to Paediatric Rehabilitation Reference Group.</p> <p>Project information used to inform 2005-06 budget submission for growth in SACs – this submission was successful.</p> <p>Final report will be placed on the Sub-acute Services website and will inform further policy development.</p>

## 6. Discussion / Recommendations

---

### 6.1 General

The development of specialist clinics at SVH and the RMH – including the work undertaken at the RCH to increase awareness of the importance of transition and prepare specific patients for transfer – was a complex undertaking, which required collaboration and input from a huge range of health professionals at four different sites. A key feature of this process was that it involved many staff choosing to work in new areas, with new patient groups, embracing new ideas and new ways of working. Many people contributed to the success of the project at all sites by generously supporting it, even where they were not directly involved in patient care. In all cases, some organisational change was necessary, and while this created some barriers, goodwill and leadership enabled these barriers to be overcome.

The project thus involved all the elements of a change management process, and depended for its success on the support and leadership of key people/positions within the participating Health Services, as well as on the hard work of those directly involved in caring for patients and working with their families. Without the combination of executive level support and medical leadership at the RCH, SVH and the RMH, the clinics would not have been successfully established, nor patients successfully transferred. However, the third key role was that of a designated project worker (Clinic Coordinator) at each site, with time allocated to the project. Experience during the project indicated that the amount of time allocated to the Coordinator roles was important. At the RMH the Clinic Coordinator had less designated project time, and this may have contributed to a slower start at that site. A full time Transition Project Officer at RCH (though note that only 0.5 of her time was directly devoted to this project) was also crucial. This project worker was able to function as a resource and even occasional backfill for the part time project workers at the other sites.

#### **Recommendation:**

**At both paediatric and adult health services, the following roles should be identified and prepared to support the ongoing development of services for new patient groups and the transfer process:**

- **Executive level support**
- **Medical leadership**
- **Project worker who can champion the implementation, and has a realistic amount of time to spend on the project.**

A strength of the project was the open communication and information sharing between participants. An important result of this was that all participants – working in both the paediatric and adult systems – developed a clear understanding of the needs of young adults with complex conditions, and the principles of good transition practice (see Appendices 5 and 6).

#### **Recommendation:**

**At both paediatric and adult health services, the rationale for a formal transition process, and the medical and other needs of young adults with complex conditions should be well communicated.**

### 6.2 Clinic design and approach

The RMH and St Vincent's clinics have evolved their own specific clinic models based on site visits to MMC and the RCH clinics, and further developed in line with their own experience and expertise in running SACS. Clinic models are still evolving and further development is still occurring; they are currently in a "bedding down" phase. Feedback has been received from clients, and will provide an important source of guidance for further development.

A key learning of the project was that the development of new services of this sort requires time, consultation, and clear communication. The development of clinics has to be inclusive, with all health professionals and administrative staff at every stage of planning and implementation.

Differences in clinic models are appropriate given the different patient groups the clinics are designed for, and the different organisational structures and specialities within the two Health Services. However both clinics are working with clients with complex needs and disabilities, and thus have developed some important features in common due to this. These features include:

- Timing/length
  - 2-3 hours each, staggered appointments
- Venue
  - Needs to be on the ground floor, wheelchair accessible
- Staff present during consultations
  - Core group of medical specialists including rehabilitation physicians, Occupational Therapy, Physiotherapy, Coordinator/Transition Project Officer
- Core specialist assessments required
  - Physiotherapy, Occupational Therapy, Social Work, Dietetics
- Referrals to a wide variety of community-based resources and other programs
  - For example, community physiotherapist, wheelchair prescribing, recreation, continence clinic, sexual health, urology and other medical referrals
- Management of documentation and dissemination of transfer summary
  - Reviewed and refined after each clinic, ensure this information is available well in advance of clinic date e.g. 2-4 weeks prior to clinic
- Equipment required
  - Examination bed, toilets for disabled, feeding cubicles
- Other key learnings
  - Attention to practical matters is crucial for patient and family satisfaction with the transfer process and their new health care provider. For example clinic times should avoid school holidays; simple resources such as maps, amenities and parking information serve to allay anxiety and increase patients' comfort and trust in their new situation; parking close to the clinic eases stress for families; the Coordinator should ideally telephone one day prior to confirm booking, and be available to meet the patient at the entrance to the clinic.

**Recommendation:**

**Resources for patients and their families should include**

- **access to disabled parking**
- **information about transport and parking**
- **maps of the hospital and the local area**
- **information about other amenities such as the cafeteria**
- **Clinic times should be scheduled to suit patients and their families/carers, taking into account school holidays and the demands of work**

One issue that was identified during the project was the need to ensure that Emergency Departments are aware of the patients who attend these clinics. Many patients in these groups will need to access Emergency during acute exacerbations of their conditions, and their interaction with the sub-acute specialists needs to be flagged to ensure coordinated care.

**Recommendation:**

**Clinics should develop appropriate mechanisms for informing Emergency Departments that a presenting patient attends the young adults with complex disability clinic.**

Key staff roles identified for the clinics comprise:

- **Executive sponsors**
- **Clinic Coordinator**
- **Medical leadership**
- **Multidisciplinary team**
  - **Physiotherapy, Occupational Therapy, Dietetics, Orthotics, Pharmacy**
- **Other medical and allied health input, including orthopaedics, urology, gastroenterology**
- **Administration**
  - **Clinic reception, clinic manager**

### **6.3 Transition policy and process at the RCH**

Transition policy needs to be clearly articulated and an implementation champion and effective medical leadership are needed to progress it. The coordinator role is key to the success of transition; it needs support and strategic positioning within the organisational structure, to achieve effective work and indicate high level support.

**Recommendation:**

**The RCH should continue to maintain and support a formal transition policy and a full time Transition Project Worker.**

Record keeping practices should take into account the information requirements of adult clinics. Transfer information should be provided to the adult clinic well in advance of patients' first appointment so as to ensure that staff are fully informed of the potential needs of the patient.

**Recommendation:**

**That the RCH develop detailed guidelines indicating the information that should be kept in the medical record and provided on a transfer summary to ensure a streamlined, concise, multidisciplinary document for the adult clinic (refer to Appendix 4).**

One experience showed that not all patients identified as ready for transfer were able to attend the scheduled clinic dates. It would be useful to develop lists of patients 'transfer ready' so that opportunities to attend specific clinic dates can be maximised, for both flexibility and patient convenience.

As there has been such a prolonged period where there have been few settings to refer these complex patients to, some work practices and time allocation require a review within the CDR Department. This is to ensure that patients arrive with clinic staff fully briefed on the new client and armed with necessary information to begin the lifelong relationship they are embarking upon.

**Recommendation:**

**That the RCH develop administrative processes to ensure that a list of patients ready to transfer is available to ensure that flexibility in setting clinic dates can be maximised.**

Key project learnings relating to the transition process for patients with complex medical needs are that:

- **Transition needs to be individually tailored for complex patients.**
- **Flexibility is essential.**
- **Provided they have information, prior knowledge and all relevant facts, patients and families are generally positive about the prospect and experience of transfer.**

**Recommendation:**

**That patients and families are provided with opportunities for discussion about transition and information to assist them to understand the issues they may encounter in their transfer to the new hospital. Adult clinic staff should also receive some information explaining difficulties for patients and their families in transferring to a new hospital.**

#### **6.4 Information Sharing**

Throughout the project, Southern Health provided expert clinical advice and guidance about working with these patient groups as well as the issues, needs and expectations of young adults with complex medical needs. Activities included:

- Staff from each new clinic site attended MMC clinics.
- Staff from MMC attended adult clinics .
- Staff from MMC attended and contributed to education and information sharing sessions.
- Staff from MMC provided advice on approaches to and practicalities of running clinics for the target patient groups.
- Key Southern Health staff provided secondary consultation

RCH staff also worked with their counterparts at SVH and the RMH throughout the project. Their activities included:

- RCH staff provided two afternoon sessions at each site with condition-specific information and case presentations.
- RCH medical staff and community physiotherapists have also provided support to the RMH clinic.

The opportunity for colleagues from different organisations to work together and exchange knowledge and expertise was crucial to the success of the project. It is envisaged that informal visits by key 'experts' will continue to occur periodically through consultation between Clinic Coordinators and the Project Officer.

**Recommendation:**

**That ongoing mechanisms for collaboration and knowledge sharing among professionals at different Health Services providing care for people with complex medical needs and disabilities are developed and implemented. This is a key responsibility of the current Project Officer. This role risks being neglected if it is not explicitly included as part of a position description.**

#### **6.5 General Learnings from the Project**

The current strategy of condition specific clinics (cerebral palsy patients attending SVH and spina bifida patients the RMH) is useful because:

- The likelihood of patients with cerebral palsy becoming acutely ill is greater than for patients with spina bifida and the clinic at St Vincent's is on the same site as their ED. It is therefore better set up logistically to manage these patients.
- The RMH clinic does not yet have the capacity to systemically link with the RMH Emergency Department; e.g. different patient records are kept, they are geographically separate.
- This offers an opportunity for development and consolidation of clinical expertise in each clinic.

**Recommendation:**

**To maintain condition specific clinics at this juncture .**

While clinics at SVH and the RMH are currently focussing on transitioning young adult patients from the RCH, it has been acknowledged that in the future clients will emerge from the community (due to previously unmet need). Adult Health Services involved in piloting

these “transition clinics” are in fact developing clinical expertise that will enable them to provide appropriate ongoing care for older adults in these particular patient groups. As knowledge of these new clinics is disseminated patients are already beginning to contact the clinics. Two patients have recently been referred from community therapists.

Experience at MMC shows that the existence of a specialist clinic of this sort attracts many more clients than they are able to currently manage. It is essential that the expertise and capacity of the clinics is reviewed and maintained so they are equipped to manage the emerging demand.

There is now an opportunity to examine other areas of unmet need for healthcare among people with disabilities and complex medical needs and pilot further clinics. For example, the withdrawal of BHCG from the project has meant that there is still an issue with access to services for many people in rural Victoria, and that no specific model for providing services in a regional and/or rural setting has been identified. Further demographic analysis may be valuable.

**Recommendation:**

**Further opportunities for establishing services for people with complex medical needs and disabilities should be identified, and piloting should continue.**

Regular review of effectiveness of clinics, system processes and documentation of family satisfaction and health outcomes for patients are all important aspects of the transition project that must be evaluated.

**Recommendation:**

**That an evaluation framework for the new clinics be developed, encompassing quality, health outcomes and consumer satisfaction.**

## **7. Summary of Recommendations**

---

1. At both paediatric and adult health services, the following roles should be identified and prepared to support the ongoing development of services for new patient groups and the transfer process:

- Executive level support.
- Medical leadership.
- Project worker who can champion the implementation, and has a realistic amount of time to spend on the project.

2. At both paediatric and adult health services, the rationale for a formal transition process, and the medical and other needs of young adults with complex conditions should be well communicated.

Resources for patients and their families should include:

- Access to disabled parking.
- Information about transport and parking.
- Maps of the hospital and the local area.
- Information about other amenities such as the cafeteria.
- Clinic times should be scheduled to suit patients and their families/carers, taking into account school holidays and the demands of work.

3. Clinics should develop appropriate mechanisms for informing Emergency Departments that a presenting patient attends the young adults with complex disability clinic.

4. The RCH should continue to maintain and support a formal transition policy and a full time Transition Project Worker.

5. The RCH should develop detailed guidelines indicating the information that should be kept in the medical record and provided on a transfer summary to ensure a streamlined, concise, multidisciplinary document for the adult clinic.

6. The RCH should develop administrative processes to ensure that a list of patients ready to transfer is available to ensure flexibility in setting clinic dates can be maximised.

7. That patients and families should be provided with opportunities for discussion about transition and information to assist them to understand the issues they may encounter in their transfer to the new hospital. Adult clinic staff should also receive some information around difficulties for patients and their families in transferring to a new hospital.

8. Ongoing mechanisms for collaboration and knowledge sharing among professionals at different Health Services providing care for people with complex medical needs and disabilities should be developed and implemented.

9. Condition specific clinics should be maintained at this juncture .

10. Further opportunities for establishing services for people with complex medical needs and disabilities should be identified, and piloting should continue.

11. An evaluation framework for the new clinics should be developed, encompassing quality, health outcomes and consumer satisfaction.

## **8. Conclusion**

---

The continued enthusiasm and support of all personnel involved in the creation of these clinics has been the key to the project's success so far. For its continued success the following elements are needed:

- An understanding that these clinics are a dynamic process.
- The establishment of new clinics within an existing service system framework, such as the SACS Framework.
- A regular review process with an open attitude to constructive feedback from patients, colleagues and families.
- Mutual respect for all disciplines involved in the multidisciplinary clinic process.
- Excellent communication mechanisms.
- Understanding and awareness that these young adults are entitled to access adult services.
- Continued skill sharing and mentoring to enable these patients to receive appropriate care in the right place and at the right time.

## 9. Bibliography

---

Pei-Yoong Lam, Bronwyn B Fitzgerald and Susan M Sawyer (2005) Young adults in children's hospitals: why are they there? *Medical Journal of Australia* 2005; 182 (8): 381-384

Sawyer, S. M., Collins, N., Bryan, D., Brown, D., Hope, M. A., & Bowes, G. (1998). Young people with spina bifida: Transfer from paediatric to adult health care. *Journal of Paediatric and Child Health*, 34, 414-417.

Hyperlinks to articles used in this report

[Smoothing the transition to adult care](#)

[Transition from paediatric to adult care. Bridging the gaps or passing the buck?](#)

[A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs](#)

[Young adults in children's hospitals: why are they there?](#)

Full list of references (Appendix 8)

## 10. Appendices

---

### Appendix 1

#### **Transfer of Young Adults with Complex Needs Project Working Party Terms of Reference**

##### **Aim:**

To monitor and facilitate the progress of the Transfer of Young Adults with Complex Medical Needs project.

##### **Tasks:**

1. Advising on the development of the project plan, monitoring project progress in relation to the plan, and advising on the revision of the project plan as issues emerge.
2. Determining which patients will participate in the project.
3. Determining the most effective approach for rolling out the project at participating Health Services, including consideration of models of care and other clinical issues.
4. Supporting the implementation of the project at participating Health Services.
5. Overseeing the work of, and receiving reports from, a Project Officer.
6. Identifying broader policy issues emerging from the project and reporting on them to the Paediatric Rehabilitation Reference Group or key policy areas within the Department, as appropriate.
7. Advising on and reviewing documents regarding the transition of young adults with complex medical needs from the paediatric service system to the adult service system. Such documents may include guidelines, protocols and DHS policy documents.

## Membership:

Dr Geoff Abbott	Deputy Director of Rehabilitation, Melbourne Health	<a href="mailto:geoff.abbott@mh.org.au">geoff.abbott@mh.org.au</a>
Chris Blackburn	Physiotherapy, Southern Health	<a href="mailto:c.blackburn@southernhealth.org.au">c.blackburn@southernhealth.org.au</a>
Dr Genevieve Kennedy	Group Manager, Rehabilitation, St Vincent's Health	<a href="mailto:Genevieve.KENNEDY@svhm.org.au">Genevieve.KENNEDY@svhm.org.au</a>
Dr David Murphy	Clinical Director, Rehabilitation, Bendigo Healthcare Group	<a href="mailto:Dmurphy@bendigohealth.org.au">Dmurphy@bendigohealth.org.au</a>
Dr Barry Rawicki	Head of Unit, Rehab, RASP, Southern Health	<a href="mailto:barry.rawicki@southernhealth.org.au">barry.rawicki@southernhealth.org.au</a>
Dr Dinah Reddihough	Paediatrician and Rehabilitationist, RCH	<a href="mailto:dinah.reddihough@rch.org.au">dinah.reddihough@rch.org.au</a>
Leanne Shea	RCH, NUM Adolescent Unit	<a href="mailto:leanne.shea@rch.org.au">leanne.shea@rch.org.au</a>
Susan Race	Manager, Sub-acute Ambulatory Care Services	<a href="mailto:susan.race@dhs.vic.gov.au">susan.race@dhs.vic.gov.au</a>
Maree Roberts	Acting Manager, Hospital Demand Management	<a href="mailto:maree.roberts@dhs.vic.gov.au">maree.roberts@dhs.vic.gov.au</a>
Miriam Segon-Fisher	Manager, Specialist Services, Community and Individual Support, Disability Services	<a href="mailto:miriam.segon-fisher@dhs.vic.gov.au">miriam.segon-fisher@dhs.vic.gov.au</a>
Adina Hamilton	Senior Project Officer, Continuing Care	<a href="mailto:adina.hamilton@dhs.vic.gov.au">adina.hamilton@dhs.vic.gov.au</a>

## Administration:

- Susan Race will chair the Working Group.
- The Project Officer will also attend Working Group meetings.
- The tenure of the Working Group is for the duration of the project, which is expected to be six months from the date at which the Project Officer is employed.
- The Working Group will meet every 6 weeks, with a break over December-January. Communication, including the circulation of draft documents for feedback, will take place via email in between meetings. Currently scheduled meeting dates are:
  - **25 August 2004**
  - **6 October 2004**
  - **17 November 2004**
  - **16 February 2005**
  - **30 March 2005**
  - **11 May 2005**

## Appendix 2 Project Officer Position Description

<b>Title:</b>	<b>Transition Project Officer</b>
<b>Grade:</b>	Senior clinician
<b>Salary:</b>	Within appropriate range for grade, pro-rata if part-time
<b>Employment Status:</b>	Applicants who wish to work both full-time and part-time will be considered. Part-time applicants must be able to work at least 0.5 EFT.
<b>Contact for Information:</b>	Adina Hamilton
<b>Telephone No:</b>	9616 1332
<b>Reference No:</b>	
<b>Applications Close:</b>	22 October 2004

### Work Environment

The Transition Project Officer will work to improve the transition of young adults with complex medical needs from the Royal Children's Hospital to the adult service system.

The position will be based at the Royal Children's Hospital. There will be some travel to the participating Health Services (Melbourne Health, St Vincent's Health, the Bendigo Healthcare Group, and Southern Health).

The Transition Project Officer will report to the Project Working Group.

### Purpose of the Job:

- To manage a six-month project to transition a limited number of young adults with complex medical needs from the Royal Children's Hospital to Melbourne Health and St Vincent's Health;
- To document learnings, including successful processes and protocols, from this project; and
- To liaise between participating Health Services, support the development of services for the target group of patients, and enhance awareness of their needs.

### Key Objectives:

To manage the project, and specifically to:

- Facilitate the participating Health Services taking a coordinated approach to developing appropriate services for patients with complex medical needs, including pro-actively building and maintaining positive relationships with all project participants and key stakeholders.
- Develop protocols and other documentation for the transition process, in consultation with clinicians and the Project Working Group.
- Develop criteria for assessing project outcomes and fully document the stages of project development and implementation, including the service model developed, at each Health Service.
- Consult and liaise with all participating Health Services to establish what support is needed to enable the successful transition of patients to the relevant adult service.
- Facilitate the provision of the requisite support for initiating the transition process. This may include:
  - Liaison and consultation with clinicians regarding the referral process.
  - Liaison with clinicians and executive sponsors regarding the organisation of new clinics.

- Communication with patients and families.
  - Organising information sharing forums and/or training sessions.
- Give regular reports to the Project Working Group on the progress of the project and produce a final written report.

### **Selection Capabilities**

Selection will be based on the skills, knowledge and personal attributes that are required for achieving the key objectives listed above.

#### *Mandatory Qualifications:*

- Qualification in a relevant health discipline.

#### *Capabilities:*

- Expertise in a relevant health discipline, experience in working in a multidisciplinary setting, and experience working with patients with complex needs and disabilities.
- Demonstrated expertise in project management, including successfully managing operational demands of projects within tight timeframes and budgetary parameters.
- Highly developed verbal communication and interpersonal skills particularly as demonstrated in the management of relationships with a diverse client base.
- Highly developed conceptual and analytical skills and the expertise to resolve complex problems and balance competing demands.
- Negotiation skills and the ability to achieve consensus and gain agreement to proposals and ideas.
- Ability to write in a clear, fluent and concise manner; produce written communications that are appropriate and readily understood by the intended audience; organise information in a logical sequence.

#### *Attributes:*

- Team Work: co-operate well and work well with others in the pursuit of team goals, share information, support others, show consideration, concern and respect for others' feelings and ideas.
- Drive and Commitment: be enthusiastic and committed, demonstrate capacity for sustained effort and hard work, set high standards of performance for self and others.
- Initiative: be proactive and self-starting, seize opportunities and act upon them, originate action and actively influence events.
- Building productive networks: be able to establish and maintain relationships with people at all levels, promote harmony and consensus through diplomatic handling of disagreements, be able to forge useful partnerships with people across business areas, functions and organisations.

## Appendix 3

### List of Consultations

#### At RCH:

- Physiotherapy
- Orthopaedics
- Nutrition and Dietetics
- Equipment Distribution Centre
- Gastroenterology
- Orthotics
- Ophthalmology
- Plastics
- Stomal Therapy
- Occupational Therapy
- Gait Laboratory
- Home and Community Care

#### Adult Hospital Departments with active involvement in clinics include:

- Rehabilitation
- Occupational Therapy
- Physiotherapy
- Stomal Therapy
- Nutrition/Dietetics
- Social Work
- Accident and Emergency

#### Work still continuing on involving the following departments, formally:

- Gastroenterology
- Orthopaedics
- Urology

#### Community consultations

- Spina Bifida Association of Victoria  
*Has maintained contact and offered to come and talk to staff at RMHRP about Spina Bifida and the work of the association*
- Association for Children with a Disability Parent to Parent Inner East  
*Provided Information /resources. Met with 8 mothers who care for children/adolescents with a Disability. Discussed many issues arising from their experiences. Minimal options available. Lack of information about services available.*
- Centre for Developmental Disability Health Victoria  
*Met with 2 medical staff at this organisation where we discussed their role and in particular the role of the GP in the care of disabled young people.*
- Moreland Community Health  
*Occupational Therapist referred a patient to RMH RP Clinic*
- Yooralla – Box Hill  
*Physiotherapist referred a patient to St. Vincent's Hospital Clinic*


**Transfer Record for [full name of patient]**

For any queries in completing this please call Felicity Sloman, Transition Coordinator ext 4858

- Instructions:**
1. Please save this document on to your computer.
  2. Complete **your** section electronically
  3. Forward document on to Transition Coordinator.

Please complete your section and return *electronically* to: [insert name] @rch.org.au]

Name of Patient	[ name of patient ]
Transfer Record commenced	[ date ]
UR	[ UR number ]
Address	[insert address here]
Contact Name / Tel / Mobile	[insert name and numbers here]
DOB	[ date of birth ]
Diagnosis(es)	[ main diagnosis/es ]
Name of receiving Doctor/Clinic in Adult Hospital	[insert name of Doctor/Clinic hospital here]
<b>Past History</b>	
Department: Contact: Dr Tel: 9345	[ insert transfer information here ]
Department: Contact: Dr Tel: 9345	[ insert transfer information here ]
Department: Contact: Tel:	[ insert transfer information here ]
Allied Health: e.g. <i>Physio, OT, Speech, Nutrition</i> Contact: Tel:	[ insert transfer information here ]
Nursing Care Manager: Tel: (include <a href="#">Disability Profile</a> if appropriate)	[ insert transfer information here ]

**Extend document as necessary**

**Please send copy of this transfer record to the following people and.....TICK Box**

Person/Institution	Name	Address	✓
adult health care setting			
patient/family			
general practitioner			
RCH health information services			
transition coordinator			
other...			

More blank transfer proformas available at:

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

## Transition Pathway

Each clinical area should have a transition pathway which details how transition should occur for most young people in their care. The information below details what should be included in the pathway.

- ❖ **Name of clinical area + location**
- ❖ **Members of team involved in transition**  
<include individual role in transition>
- ❖ **Transition age**  
<statement of:
  - a. the age at which transition should commence
  - b. How and by whom transition will be introduced to the young person and family
  - c. Target age for completion>
- ❖ **Major Transition Issues**  
<list any issues that may impact on the transition process specific to this chronic illness group>
- ❖ **Adult health services**  
<list the adult health services that are appropriate to assume the care of young people. Include acute and non acute services>  
< Include how communication lines are to be maintained between your paediatric team and the adult teams>
- ❖ **Involvement of government & community groups**  
<Note any groups (NGO's, educational services, ) which should be included in the transition process and how they will be included>
- ❖ **Transition Planning Checklists**  
<Develop checklists for clinicians in your clinical area that will stimulate thought and discussion about transition issues at various developmental stages> see Transition web page on RCH Intranet for basic [checklist](#)  
<State who will support and monitor the young person and their families progression through these checklists>

Checklists should be considerate of and include the following:

- ⇒ Developmental and chronological age
- ⇒ Psychosocial needs
- ⇒ Physical needs
- ⇒ Increasing levels of independence
- ⇒ Understanding of illness
- ⇒ Self advocacy
- ⇒ Sexual health
- ⇒ Education and vocational planning
- ⇒ Progressive self management of illness/condition
- ⇒ Health and adolescent lifestyle issues
- ⇒ Parental/caregiver needs

The RCH Transition Project has developed checklists as part of their Transition Web page These can be adapted to specific clinical areas. You can access this information through the project website (<http://www.rch.org.au/transition> )

- ❖ **Toolkit for young people and families/caregivers**  
< Develop a 'toolkit' for distribution to young people and their families>  
<Include who is responsible for updating and distributing the toolkit>

Toolkits should include written information about

- ⇒ The young person's individual transition plan
- ⇒ What the young person's role and responsibilities are
- ⇒ The differences they may face between the paediatric and adult settings
- ⇒ Tips for increasing their independence and knowledge of the adult 'medical world'.
- ⇒ Specific information about their condition/illness
- ⇒ Where to find out more information (contact person, telephone numbers and websites)

The RCH Transition Project has developed a toolkit to assist with transition. (*adapted from NSW Transition Project*). It includes generic fact sheets (for young people, families and professionals which can be adapted to specific clinical areas), checklists, links to transition websites and references. You can access this information through the Transition website: <http://www.rch.org.au/transition>

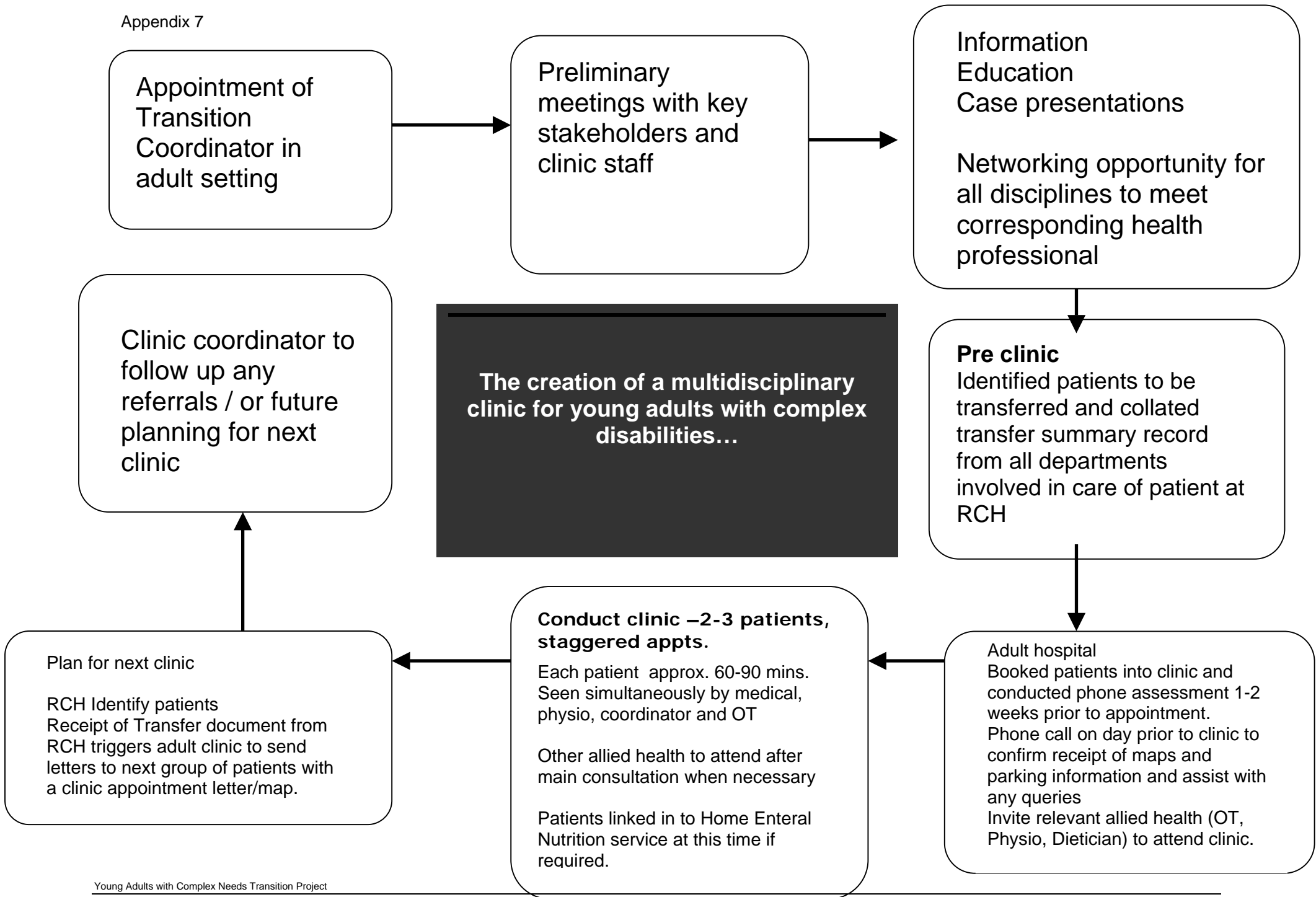
- ❖ **Transition Model (see example)**  
<Include models or care, proforma for individual transition plans, timelines, team transition meetings, how adult services will be incorporated, joint management arrangements>
  
- ❖ **Evaluation of the transition process**  
<Note how the team intends to provide regular on going evaluation of the transition process through surveys and information gathering from young people, families and clinicians>  
<Include the frequency of evaluation (such as every six months, or annually)>  
<Include how evaluation will be incorporated into the revision of the transition pathway and individual transition plans>  
***Based on a Pathway developed by NSW Transcare Project***

## Appendix 6

### **Principles of Transition**

The following Principles have been established to assist with the future development of Transition processes and clinics.

- Initiate discussion regarding transition in early/mid adolescence as an integral part of the overall health care plan thus making it a normal part of caring for an adolescent with a chronic illness. This has been done in the past by CDR staff but it is important to ensure that this process is systematic, thorough and that opportunity is provided to allow families to discuss their issues and concerns.
- Young people and their family's inclusion in the development of the individual transition plan is vital to the success of the process. Young people and/or their families are required to gain a significant number of new skills during the transition process. Their families and carers are often faced with a change in their role from that of primary carer to support provider. (Fact sheets on RCH website)
- Prepare patient and carers for a different system in a constructive and informative manner. Adult hospitals do run differently. Provision of specific information about ongoing care provision and by whom is essential. If services are not available explore other options for care with family.
- Encourage families and patients to be assertive and as necessary to be a strong advocate for their son/daughter. This may be included in an education program.
- Develop transition programs to address common concerns of young people including growth and development, sexuality, mood and other health promoting and damaging behaviours.
- Carers need to recognise the importance of promoting the young persons' increasing capacity for self care (commensurate with their ability)
- A team approach is essential in order to provide a multi disciplinary transfer document involving medical, nursing and allied health staff for the receiving adult setting.
- Attention should be paid to ongoing collaboration with adult hospitals that will need to accept the responsibility of young adult patients. This requires regular communication between paediatric and adult health care services to enable clear processes to be developed for the successful transition of young people to adult services.
- A target age for the beginning and ending of transition should be established for each patient group. The process of transition will generally begin around age 13 to 14 years old. Even though the transfer to adult care may occur in late adolescence (17-18 years old), it is important to prepare adolescents for the move well in advance of this event. This is to allow enough time for the planning and organisation of transfer to adult services, the development of skills, detaching from the paediatric service and becoming familiar with adult services. It is understood that there will be significant variance between young people and adjustments in the timing of transition will be required to accommodate their individual needs. Consideration should be given to the timing of the transfer to adult care so as not to coincide with a young person's final school year, if this is a consideration. This is recognised as a challenging time as the young person may be preparing for exams and the life changes that will soon occur. Undertaking transfer well before this time, or delaying the transfer to adult services until after the Year 12, is advisable.
- The timing of transition to adult healthcare needs to occur within a developmental context as well as consideration of chronological age. Whilst the target age for transfer to adult services should be individually assessed, the maximum age for the completion of transition should be before the young person's 20<sup>th</sup> birthday. (RCH Policy)



**REFERENCES on TRANSITION**

---

**Royal Children's Hospital Transition Project  
With thanks to NSW Transcare Project- Lynn Brodie et al.**

**Updated March 2005**

- Alper, S. (1990). Parents' perceptions of transition programs for youth with severe handicaps. *Canadian Journal of Rehabilitation*, 3(4), 205-212.
- American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians-American Society of Internal Medicine (2002). 'A Consensus Statement of Health Care Transitions for Young People with Special Health Care Needs. *Pediatrics*, 110 (6) 1304-1306.
- American Academy of Pediatrics Committee on Children with Disabilities and Committee on Adolescence (AAP) (1996). 'Transition of care for adolescents with special health care needs'. *Pediatrics*, 98(6), 1203-1206.
- Antle, B. Anderson, D. Phillips, A. (2001) More on my own: A pilot Transitional education Program for Children with Inborn Errors of Metabolism. *Poster Presentation to 39<sup>th</sup> SSIEM Symposium in Prague Czech Republic September 2001*.
- Aune, E. (1991). A transition model for postsecondary-bound students with learning disabilities. *Learning Disabilities Research & Practice*, 6, 177-187.
- Backhouse M., Rodger S. (1999). 'The transition from school to employment for young people with acquired brain injury: Parent and student Perceptions'. *Australian Occupational Therapy Journal*, 46, 99-109
- Barry, R (ed) (2004). *The Law Handbook*. Redfern Legal Centre Publishing, University of NSW, Australia.
- Bates, K., Bartoszesky, L., & Friedland, A. (2003). As the child with chronic disease grows up: Transitioning adolescents with special health care needs to adult-centred health care. *Delaware Medical Journal*, 75(6), 217-220.
- Beecham, J., O'Neill, T., & Goodman, R. (2001). Supporting young adults with hemiplegia: Services and costs. *Health and Social Care in the Community*, 9(1), 51-59.
- Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, health and development*, 30(6), 581-587.
- Berkell, D. E. (1992). Transition issues for secondary school students with autism and developmental disabilities. In F. R. Rusch, L. Destefano, J. Chadsey-Rusch, L. A. Phelps & E. Szymanski (Eds.), *Transition from school to adult life: Models, linkages and policy* (pp. 459-472). Sycamore: Sycamore Publishing Company.
- Betz, C. L. (1998a). Adolescent transitions: A nursing concern. *Pediatric Nursing*, 24(1), 23-30.
- Betz, C. L. (1998b). Facilitating the transition of adolescents with chronic conditions from pediatric to adult health care and community settings. *Issues in Comprehensive Pediatric Nursing*, 21, 97-115.
- Betz, C. L. (1999). Adolescents with chronic conditions: Linkages to adult service systems. *Pediatric Nursing*, 25(5), 473-476.

- Bhakta, B. B., & Chamberlain, M. A. (2001). Transition from paediatric clinic to the adult service. *Journal of the Royal Society of Medicine*, 94(12), 659.
- Blackorby, J., & Wagner, M. (1996). Longitudinal post school outcomes of youth with disabilities: Findings from the national longitudinal transition study. *Exceptional Children*, 62(5), 399-413.
- Blalock, G. (1996). Community transition teams as the foundation for transition services for youth with learning disabilities. *Journal of Learning Disabilities*, 29(2), 148-158.
- Blomquist, K. B., Brown, G., Peersen, A., & Presler, E. P. (1998). Transitioning to independence: Challenges for young people with disabilities and their caregivers. *Orthopedic Nursing*, 17(3), 27-35.
- Blum, R. W. (1991). Overview of transition issues for youth with disabilities. *Pediatrician*, 18, 101-104.
- Blum, R. W. (1995). Transition to adult health care: Setting the stage. *Journal of Adolescent Health*, 17(1), 3-5.
- Blum, R. W. (2002). Introduction: The consensus statement on health care transitions. *Pediatrics*, 110(6), 1301-1303.
- Blum, R. W., Hirsch, D., Kastner, T. A., Quint, R. D., & Sandler, A. D. (2002). A consensus statement on health care transitions for young adults with special care needs. *Pediatrics*, 110(6), 1304-1306.
- Blum, R. W. M. (1990). Knowledge and attitudes of health professionals toward adolescent health care. *Journal of Adolescent Health*, 11, 289-294.
- Blum, R. W. M. (1992). Chronic illness and disability in adolescence. *Journal of Adolescent Health*, 13, 364-368.
- Blum, R. W. M., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., et al. (1993). Transition from child-centred to adult health-care systems for adolescents with chronic conditions: A position paper of the society for adolescent medicine. *Journal of Adolescent Health*, 14, 570-576.
- Blum, R.W (1995) Transition to Adult Health Care: Setting the Stage. *Journal of Adolescent Health*,17:3-5
- Blum R., Garell D., Hodgman C., Slap G. (2003). 'Transition from Child-centered to Adult Health Care'. [www.adolescenthealth.org/html/transition\\_html](http://www.adolescenthealth.org/html/transition_html), 15/7/2003, pp1-8.
- Bowes, G., Sinnema, G., Suris, J-C., Buhlmann, U. (1995). Transition Health Services for Youth with Disabilities: A Global Perspective. *Journal of Adolescent Health*. 17 (1) 25-31.
- Bowes, G., Sinnema, G., Suris, J.-C., & Buhlmann, U. (1995). Transition health services for youth with disabilities: A global perspective. *Journal of Adolescent Health*, 17(1), 23-31.
- Brinckerhoff, L. C. (1996). Making the transition to higher education: Opportunities for student empowerment. In J. R. Patton & G. Blalock (Eds.), *Transition and students with learning disabilities: Facilitating the movement from school to adult life* (pp. 157-189). Austin: Pro-Ed.
- Brain Injury Association of NSW. *Brain Injury – Fact Sheets*. Brain Injury Association of NSW, Sydney.

- Brain Injury Association of Queensland (2003). *Fact Sheets*. Brain Injury Association of Queensland. [www.biaq.com.au](http://www.biaq.com.au)
- Brands, C. Sharma, N. Transitional Medicine: Perspectives and Challenges from the MPPDA Committee on Transitional Care
- Brodin, J., & Fasth, A. (2001). Habilitation, support and services for young people with motor disabilities: A Swedish perspective. *International Journal of Rehabilitation Research*, 24(4), 309-316.
- Brollier, C., Shepherd, J., & Flick Markley, K. (1994). Transition from school to community living. *The American Journal of Occupational Therapy*, 48(4), 346-353.
- Brotherson, M. J., Houghton, J., Turnbull, A. P., Bronicki, G. J., Roeder-Gordon, C., Summers, J. A., et al. (1988). Transition into adulthood: Parental planning for sons and daughters with disabilities. *Education and Training in Mental Retardation*, 23(3), 165-174.
- Brumfield K, Lansbury, G.,(2004) Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a quantitative study of young Australian adults. *Disability Rehabilitation*, 18;26 (4) 223-34
- Buran, C. F., Sawin, K. J., Brei, T. J., & Fastenau, P. S. (2004). Adolescents with myelomeningocele: Activities, beliefs, expectations, and perceptions. *Developmental Medicine & Child Neurology*, 46(4), 244-252.
- Callahan, S. T., Winitzer, R. F., & Keenan, P. (2001). Transition from pediatric to adult-oriented health care: A challenge for patients with chronic disease. *Current Opinion in Pediatrics*, 13, 310-316.
- Cappelli, M., MacDonald, N. E., & McGrath, P. J. (1989). Assessment of readiness to transfer to adult care for adolescents with cystic fibrosis. *Children's Health Care*, 18(4), 218-224.
- Chamberlain, M. A. (1993). Physically handicapped school leavers. *Archives of Disease in Childhood*, 69(3), 399-402.
- Chamberlain, M. A., & Guthrie, S. (1996). The approach of rehabilitation services. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 75-83). London: Royal College of Physicians of London.
- Chandler, J., O'Brien, P., & Weinstein, L. (1996). The role of occupational therapy in the transition from school to work for adolescents with disabilities. *Work*, 6, 53-59.
- Clark, G. M. (1996). Transition planning assessment for secondary-level students with learning disabilities. In J. R. Patton & G. Blalock (Eds.), *Transition and students with learning disabilities: Facilitating the movement from school to adult life* (pp. 131-156). Austin: Pro-Ed.
- Cohen, P., Kasen, S., Chen, H., Hartmark, C., & Gordon, K. (2003). Variations in patterns of developmental transitions in the emerging adulthood period. *Developmental Psychology*, 39(4), 657-669.
- Connolly, B. H. (2001). Transition from childhood to adulthood. *Physical & Occupational Therapy in Pediatrics*, 21(4), 1-2.

- Conway, S. P. (1998). Transition from paediatric to adult-orientated care for adolescents with cystic fibrosis. *Disability and Rehabilitation*, 20(6/7), 209-216.
- Court, J. M. (1993). Issues of transition to adult care. *Journal of Pediatric and Child Health*, 29(Supp 1), S23-S55.
- Cowlard, J. (2003). Cystic fibrosis: Transition from paediatric to adult care. *Nursing Standard*, 18(4), 39-41.
- Cronin, M. E. (1996). Life skills curricula for students with learning disabilities: A review of the literature. In J. R. Patton & G. Blalock (Eds.), *Transition and students with learning disabilities: Facilitating the movement from school to adult life* (pp. 85-112). Austin: Pro-Ed.
- Court, J. M. (1993). Issues of transition to adult care. *Journal of Pediatric and Child Health*, 29(Supp 1), S23-S55.
- Dattilo, J., & St. Peter, S. (1991). A model for including leisure education in transition services for young adults with mental retardation. *Education and Training in Mental Retardation*, 26(4), 420-432.
- Davis, P. K., & Pancsofar, E. L. (1999). Living in the community. In P. Wehman & P. S. Targett (Eds.), *Vocational curriculum for individuals with special needs: Transition from school to adulthood* (pp. 111-130). Austin: Pro-Ed.
- Dempsey, I. (2001). Transition from school. In P. Foreman (Ed.), *Integration and inclusion in action* (2nd ed., pp. 431-450). Melbourne: Thomson.
- DeStefano, L. (1990). Needed research on evaluation: Approaching it from the context of transition programs for handicapped adolescents. *Studies in Educational Evaluation*, 16, 197-207.
- Dick, M-L. (2003) Chronic illness in young Australian adults. *Medical Journal of Australia* 179 (5) 238
- Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology*, 22(2), 149-165.
- Field, S. (1996). Self-determination instructional strategies for youth with learning disabilities. In J. R. Patton & G. Blalock (Eds.), *Transition and students with learning disabilities: Facilitating the movement from school to adult life* (pp. 61-84). Austin: Pro-Ed.
- Ferguson, P. M., Ferguson, D. L., & Jones, D. (1998). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, 13(3), 177-187.
- Fiorentino, L., Datta, D., Gentle, S., Hall, D. M. B., Harpin, V., Phillips, D., et al. (1998). Transition from school to adult life for physically disabled young people. *Archives of Disease in Childhood*, 79(4), 306-311.
- Fiorentino, L., Phillips, D., Walker, A., & Hall, D. (1998). Leaving paediatrics: The experience of service transition for young disabled people and their family carers. *Health and Social Care in the Community*, 6(4), 260-270.
- 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. *Journal of Clinical Nursing*, 11, 560-567.

- Flume, P. A., Anderson, D. L., Hardy, K. K., & Gray, S. (2001). Transition programs in cystic fibrosis centres: Perceptions of pediatric and adult program directors. *Pediatric Pulmonology*, 31, 443-450.
- Fox, A. (2002). Physicians as barriers to successful transitional care. *International Journal of Adolescent Medicine and Health*, 14(1), 3-7.
- Furney, K. S., Hasazi, S. B., & Destefano, L. (1997). Transition policies, practices, and promises: Lessons from three states. *Exceptional Children*, 63(3), 343-355.
- Gallivan-Fenlon, A. (1994). "Their senior year": Family and service provider perspectives on the transition from school to adult life for young adults with disabilities. *Journal of the Association for Persons with Severe Handicaps*, 9(1), 11-23.
- Geenen, S. J., Powers, L. E., & Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*, 32(3), 225-233.
- Grant, S., & Cole, D. (1998). Young people's aspirations. In C. Robinson & K. Stalker (Eds.), *Growing up with a disability* (pp. 177-188). London: Jessica Kingsley Publishers.
- Gutman, S. A. (1999). Case report. The transition through adult rites of passage after traumatic brain injury: Preliminary assessment of an occupational therapy intervention. *Occupational Therapy International*, 6(2), 143-158.
- Hallum, A. (1995). Disability and the transition to adulthood: Issues for the disabled child, the family, and the pediatrician. *Current Problems in Pediatrics*, 25, 12-50.
- Halpern, A. S. (1985). Transition: A look at the foundations. *Exceptional Children*, 51(6), 479-486.
- Halpern, A. S. (1991). Transition: Old wine in new bottles. *Exceptional Children*, 58(3), 202-210.
- Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. M. (1995). The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life. *Journal of the Association for Persons with Severe Handicaps*, 20(1), 3-15.
- Haring, K. A., & Lovett, D. L. (1990). A follow-up study of special education graduates. *The Journal of Special Education*, 23(4), 463-477.
- Hartman, A., DePoy, E., Francis, C., & Gilmer, D. (2000). Adolescents with special health care needs in transition: Three life histories. *Social Work in Health Care*, 31(4), 43-57.
- Hauser, E. S., & Dorn, L. (1999). Transitioning adolescents with sickle cell disease to adult-centred care. *Pediatric Nursing*, 25(5), 479-488.
- Hayes, A. (1998). Transitions to adulthood. In J. P. Dormans & L. Pellegrino (Eds.), *Caring for children with cerebral palsy: A team approach* (pp. 491-500). Baltimore: Paul H. Brookes.
- Hendey, N., & Pascall, G. (2001). *Disability and the transition to adulthood: Achieving independent living*. Brighton: Pavilion.
- Hergenroeder, A. C. (2002). The transition into adulthood for children and youth with special health care needs. *Texas Medicine*, 98(2), 51-55.

- Hogan, D. P., & Astone, N. M. (1986). The transition to adulthood. *Annual Review of Sociology*, 12, 109-130.
- Irvin, L. K., Thorin, E., & Singer, G. H. S. (1993). Family-related roles and considerations: Transition to adulthood by youth with developmental disabilities. *Journal of Vocational Rehabilitation*, 3(2), 38-46.
- Jackson, J. (1990). En route to adulthood: A high school transition program for adolescents with disabilities. *Occupational Science*, 33-51.
- Jackson, J., Rankin, A., Siefken, S., & Clark, F. (1989). Options: An occupational therapy transition program for adolescents with developmental disabilities. 197-214.
- Johnson, S., & Wehman, P. (2001). Teaching for transition. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed., pp. 145-170). Baltimore: P.H. Brookes.
- Johnston, C. L. (1984). The learning disabled adolescent and young adult: An overview and critique of current practices. *Journal of Learning Disabilities*, 17(7), 386-391.
- Jackson, J. (1990). En route to adulthood: A high school transition program for adolescents with disabilities. *Occupational Science*, 33-51.
- Kalwinsky, D. K. (2002). Health care issues as the child with chronic illness transitions to adulthood. *Southern Medical Journal*, 95(9), 966-967.
- Kelly, A. M., Kratz, B., Bielski, M., & Mann Rinehart, P. (2002). Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics*, 110(6), 1322-1327.
- King, G. A., Cathers, T., Polgar, J. M., MacKinnon, E., & Havens, L. (2000). Success in life for older adolescents with cerebral palsy. *Qualitative Health Research*, 10(6), 734-749.
- Kipps, S., Bahu, T., Ong, K., Ackland, F. M., Brown, R. S., Fox, C. T., et al. (2002). Current methods of transfer of young people with type 1 diabetes to adult services. *Diabetic Medicine*, 19, 649-654.
- Klaas, S., & Hickey, K. (2001). Pediatric perspectives: Transition to adult care. *SCI Nursing*, 18(3), 158-160.
- Ko, B., & McEnery, G. (2004). The needs of physically disabled young people during transition to adult services. *Child: Care, health and development*, 30(4), 317-323.
- Koch, L. C. (2000). Career development interventions for transition-age youths with disabilities. *Work*, 14, 3-11.
- Kriel, R. L., Krach, L. E., Bergland, M. M., & Panser, L. A. (1988). Severe adolescent head injury: Implications for transition into adult life. *Pediatric Neurology*, 4(6), 337-341.
- Kurtz, Z., Mawer, C., & Hopkins, A. (1996). Guidelines for the transfer of young people with chronic physical disorders from paediatric to adult services. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 141-153). London: Royal College of Physicians of London.
- Logan, S. (1997). In the UK the transition from youth to adulthood of people with cerebral palsy is poorly planned and coordinated. *Child: Care, health and development*, 23(6), 479-482.

- Luther, B. (2001). Age-specific activities that support successful transition to adulthood for children with disabilities. *Orthopedic Nursing, 20*(1), 23-29.
- Marr, L. M., & Koch, L. C. (1999). The major tasks of adolescence: Implications for transition planning with youths with cerebral palsy. *Work, 13*(1), 51-58.
- Maze, M. (1996). The role of professions allied to medicine. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 69-73). London: Royal College of Physicians of London.
- McConachie, H., & Jaffa, T. (1996). Psychology of adolescent development. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 9-12). London: Royal College of Physicians of London.
- McDonagh, J. E., & Kelly, D. A. (2003). Transitioning care of the pediatric recipient to adult caregivers. *Pediatric Clinics of North America, 50*(6).
- McGinty, J., & Fish, J. (1996). Educational aspects of transition. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 99-107). London: Royal College of Physicians of London.
- McInerney, C. A., & McInerney, M. (1994). Occupational therapy and school-to-work transition: A preventive education model. *Occupational Therapy International, 1*(3), 158-173.
- Miller, S. (1996). Transition of care in adolescence. *Paediatric Nursing, 8*(9), 14-16.
- Morrow, V., & Richards, M. (1996). *Transitions to adulthood: A family matter?* York: York Publishing Services.
- Nasr, S. Z., Campbell, C., & Howatt, W. (1992). Transition program from pediatric to adult care for cystic fibrosis patients. *Journal of Adolescent Health, 13*, 682-685.
- Nisbet, J., Covert, S., & Schuh, M. (1992). Family involvement in the transition from school to adult life. In F. R. Rusch, L. Destefano, J. Chadsey-Rusch, L. A. Phelps & E. Szymanski (Eds.), *Transition from school to adult life: Models, linkages and policy* (pp. 407-424). Sycamore: Sycamore Publishing Company.
- Olsen, D. G., & Swigonski, N. L. (2004). Transition to adulthood: The important role of the pediatrician. *Pediatrics, 113*(3), e159-e162.
- Palmer, M. L., & Boisen, L. S. (2002). Cystic fibrosis and the transition to adulthood. *Social Work in Health Care, 36*(1), 45-58.
- Parker, G., & Hirst, M. (1987). Continuity and change in medical care for young adults with disabilities. *Journal of the Royal College of Physicians of London, 21*(2), 129-133.
- Peterson, P. M., Rauen, K. K., Brown, J., & Cole, J. (1994). Spina bifida: The transition into adulthood begins in infancy. *Rehabilitation Nursing, 19*(4), 229-238.
- Racino, J. A. (1992). Living in the community: Independence, support, and transition. In F. R. Rusch, L. Destefano, J. Chadsey-Rusch, L. A. Phelps & E. Szymanski (Eds.), *Transition from school to adult life: Models, linkages and policy* (pp. 131-148). Sycamore: Sycamore Publishing Company.
- Reeves, M. (1996). Preparing for sheltered open employment. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 109-117). London: Royal College of Physicians of London.

- Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics*, 110(6 Supp), 1307-1314.
- Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, 115(1), 112-120.
- Repetto, J. B., & Correa, V. I. (1996). Expanding views on transition. *Exceptional Children*, 62(6), 551-563.
- Riddell, S. (1998). The dynamic of transition to adulthood. In C. Robinson & K. Stalker (Eds.), *Growing up with a disability* (pp. 189-209). London: Jessica Kingsley Publishers.
- Rosen, D. (1995). Between two worlds: Bridging the cultures of child health and adult medicine. *Journal of Adolescent Health*, 17(1), 10-16.
- Rosenfeld, R. G. (2002). Transitioning patients with childhood-onset growth hormone deficiency to treatment in adulthood. *Journal of Pediatric Endocrinology and Metabolism*, 15, 1361-1365.
- Sands, D. J., Able-Boone, H., & Margolis, H. (1995). Live-in training experience (LITE): A transition program for youth with disabilities. *Teaching Exceptional Children*, 27(2), 19-23.
- Sawyer, S. M., Collins, N., Bryan, D., Brown, D., Hope, M. A., & Bowes, G. (1998). Young people with spina bifida: Transfer from paediatric to adult health care. *Journal of Paediatric and Child Health*, 34, 414-417.
- Scabini, E., & Galimberti, C. (1995). Adolescents and young adults: A transition in the family. *Journal of Adolescence*, 18, 593-606.
- Scal, P. (2002). Transition for youth with chronic conditions: Primary care physicians' approaches. *Pediatrics*, 110(6), 1315-1321.
- Scal, P., Evans, T., Blozis, S., Okinow, N., & Blum, R. W. (1999). Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *Journal of Adolescent Health*, 24(4), 259-264.
- Scheer, S. D., Unger, D. G., & Brown, M. B. (1996). Adolescents becoming adults: Attributes for adulthood. *Adolescence*, 31(121), 127-131.
- Schultz, A. W., & Liptak, G. S. (1998). Helping adolescents who have disabilities negotiate transitions to adulthood. *Issues in Comprehensive Pediatric Nursing*, 21, 187-201.
- Sharp, N. L. (2003). *Fitting back in: Returning to school post acquired brain injury in adolescence*. Unpublished honour's thesis, University of Western Sydney, Campbelltown, Australia.
- Sitlington, P. L. (1996). Transition to living: The neglected component of transition programming for individuals with learning disabilities. In J. R. Patton & G. Blalock (Eds.), *Transition and students with learning disabilities: Facilitating the movement from school to adult life* (pp. 43-59). Austin: Pro-Ed.
- Smyth, D. (1996). The approach of a community paediatrician. In Z. Kurtz & A. Hopkins (Eds.), *Services for young people with chronic disorders in their transition from childhood to adult life* (pp. 13-20). London: Royal College of Physicians of London.
- Spencer, J. E., Emery, L. J., & Schneck, C. M. (2003). Occupational therapy in transitioning adolescents to post-secondary activities. *The American Journal of Occupational Therapy*, 57(4), 435-441.

- Spencer, K. C. (2001). Transition services: From school to adult life. In J. Case-Smith (Ed.), *Occupational therapy for children* (4th ed., pp. 878-894). St Louis: Mosby.
- Stacey, W. A. (2001). The stress of progression from school to work for adolescents with learning disabilities: What about life progress? *Work, 17*, 175-181.
- Stewart, D. A., Law, M. C., Rosenbaum, P., & Willms, D. G. (2001). A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical & Occupational Therapy in Pediatrics, 21*(4), 3-21.
- Stineman, R. M., Morningstar, M. E., Bishop, B., & Turnbull, H. R. (1993). Role of families in transition planning for young adults with disabilities: Toward a method of person-centered planning. *Journal of Vocational Rehabilitation, 3*(2), 52-61.
- Stower, S. (1998). A role in smooth transitions. *Paediatric Nursing, 10*(5), 6.
- Suris, J.-C. (1995). Global trends of young people with chronic and disabling conditions. *Journal of Adolescent Health, 17*(1), 17-22.
- Szymanski, E. M. (1994). Transition: Life-span and life-space considerations for empowerment. *Exceptional Children, 60*(5), 402-410.
- Thompson, C. E. (1990). Transition of the disabled adolescent to adulthood. *Pediatrician, 17*, 308-313.
- Timmons, J. C., Whitney-Thomas, J., McIntyre Jr, J. P., Butterworth, J., & Allen, D. (2004). Managing service delivery systems and the role of parents during their children's transitions. *Journal of Rehabilitation, 70*(2), 19-26.
- Viner, R. (2000). Effective transition from paediatric to adult services. *Hospital Medicine, 61*(5), 341-343.
- Viner, R. (2001). Barriers and good practice in transition from paediatric to adult care. *Journal of the Royal Society of Medicine, 94*(Supp 40), 2-4.
- Webb, A. K., Jones, A. W., & Dodd, M. E. (2001). Transition from paediatric to adult care: Problems that arise in the adult cystic fibrosis clinic. *Journal of the Royal Society of Medicine, 94*(Supp 40), 8-11.
- Wehman, P. (2001a). Community transition planning. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed., pp. 77-89). Baltimore: P.H. Brookes.
- Wehman, P. (2001b). The family's role in transition. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed., pp. 61-76). Baltimore: P.H. Brookes.
- Wehman, P. (2001c). *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed.). Baltimore: Paul H. Brookes.
- Wehman, P. (2001d). Transition in the new millennium. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed., pp. 3-33). Baltimore: P.H. Brookes.
- Wehmeyer, M. L. (2001). Self-determination and transition. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed., pp. 35-60). Baltimore: P.H. Brookes.

- West, M. D. (2001). Applications for youth with orthopedic and other health impairments. In P. Wehman (Ed.), *Life beyond the classroom: Transition strategies for young people with disabilities* (3rd ed., pp. 427-448). Baltimore: P.H. Brookes.
- Westwood, A. T. R., Henley, L. D., & Willcox, P. (1999). Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatric and Child Health*, 35, 442-445.
- While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2004). Good practices that address continuity during transition from child to adult care: Synthesis of the evidence. *Child: Care, Health and Development*, 30(5), 439-452.
- White, P. H. (1997). Success on the road to adulthood: Issues and hurdles for adolescents with disabilities. *Pediatric Rheumatology*, 23(3), 697-707.
- White, P. H. (2002). Transition: A future promise for children and adolescents with special health care needs and disabilities. *Rheumatic Disease Clinics of North America*, 28, 687-703.
- Williams, W. G., & Webb, G. D. (2000). The emerging adult population with congenital heart disease. *Pediatric Cardiac Surgery Annual of the Seminars in Thoracic and Cardiovascular Surgery*, 3, 227-233.
- Zetlin, A. G., & Turner, J. L. (1985). Transition from adolescence to adulthood: Perspectives of mentally retarded individuals and their families. *American Journal of Mental Deficiency*, 89(6), 570-579.

#### Websites

- [www.rch.org.au/transition](http://www.rch.org.au/transition)
- <http://hctransitions.ichp.edu/resources.html>
- <http://www.bhiva.org/chiva/protocols/adolescent.html>
- Washinton State Adolescent Transition Resource Notebook;  
<http://depts.washington.edu/healthtr/notebook/content.html>
- [www.AbilityOnline.org](http://www.AbilityOnline.org)
- [www.diabetes.org.uk/update/autumn01/onup.htm](http://www.diabetes.org.uk/update/autumn01/onup.htm)
- [www.nephronline.org/management/adolescents2.asp](http://www.nephronline.org/management/adolescents2.asp)

**RMH RPC / RCH  
Spina Bifida  
Joint Education Session**

**Date:** Tuesday 25<sup>th</sup> January, 2005  
**Time:** 1pm-4pm  
**Venue:** Melbourne Extended Care Rehabilitation Service (MECRS)  
Poplar Road, Parkville  
1<sup>st</sup> Floor, Seminar Room, Graham Larkins Building

Program  
Start 1pm

**Welcome and Introductions**

Felicity Sloman – RCH Transition Project Officer (Facilitator)  
Fiona Bahr– MECRS Transition Coordinator & Dr Geoff Abbott (Rehab. Physician)  
Adina Hamilton – Department of Human Services

Presentations

Dr Kevin Dunne-Medical (max.30mins)

1. Overview of Spina Bifida-clinical aspects etc.
2. Adult health problems
3. Our assessment of what their needs are

Sharon Vladusic                      Physiotherapist max.20 mins

Judy Wells                              Stomal Therapist max.20 mins

Narelle Kreidl                        Social Work max. 20mins

(at some point in the afternoon we have the services of Louise Corben who has had ++ experience running multi disciplinary clinics in various places including the Spina Bifida Clinic at Monash. She will be arriving approx.3.15pm)

Case presentations - the RCH staff will participate in an informal question and answer session for the next part of the day.

**Issues for discussion**

- Equipment
- Bladder/bowel
- Pressure care
- Nuts and Bolts re transfer process
- How are we going to make it work? What has worked in the past..other models?
- Further training requirements
- Where to from here?
- Proposed MECRS Transition Clinic date?

Finish 4pm

**St. Vincent's Hospital / Royal Children's Hospital  
Monash Medical Centre  
Cerebral Palsy**

**Joint Education Session**

**Facilitators** Felicity Sloman, RCH Transition Project Officer  
Chris Graven, St Vincent's Transition Coordinator

**Date** Wednesday 2<sup>nd</sup> February

**Time** 1pm-4pm

**Venue** Room 2, Ground Floor  
Aikenhead Wing (cnr Nicholson St/Victoria Pde)

St Vincent's Hospital, Melbourne

Here is a map link:

<http://www.svhm.org.au/infoabout/locationmaps/svhmmmap.pdf>

**1pm**

**Introductions and welcome**

Dr Genevieve Kennedy, SVHM

Felicity Sloman, Facilitator-RCH Transition Project Officer

Chris Graven, St Vincent's Transition Coordinator

**RCH Team**

Dinah Reddihough-Medical

Angela Burge, Stephanie

Parsons-Physiotherapy

Margaret Rowell-Medical

Bev Touzel, Katie Hazard

Nursing

Narelle Kreidl-Social Work

Stella Dohle-Stomal Therapy

**St Vincent's Team**

Genevieve Kennedy-medical

Chris Graven-Coord

Jill Collins-Medical

Kim Brock- Physio

Sarah Wallace OT

Priya Davis P + O

Lisa Braddy-Social Work

Natalie Simmance - Dietitian

Janine Simondson-Physio

Libby Doyle – Dietitian

Sue Wilson- Speech

**Monash Team**

**Chris Blackburn-  
Physio**

Brian Hoare-OT

**Program**

Overview Cerebral Palsy

Nursing

Physio & CP

Social Work

Stomal Therapy

Overview of patients who are planning to transfer – RCH Team

Dinah Reddihough

Bev Touzel/Katie Hazard

Stephanie Parsons/Angela Burge

Narelle Kreidl

Stella Dohle

(max 15mins)

(max 15 mins)

(max 15 mins)

(max 15 mins)

(max 15 mins)

These cases should form the basis for discussion around all aspects of their care and issues that may arise. Other issues for discussion may include:

<ul style="list-style-type: none"> <li>• Gastrostomy review</li> <li>• Feeds</li> <li>• Role of the Family</li> <li>• Equipment/Wheelchairs</li> <li>• Bladder/bowel</li> </ul>	<ul style="list-style-type: none"> <li>• Pressure care</li> <li>• Social work issues</li> <li>• Psycho/social etc....</li> <li>• When to hold 1<sup>st</sup> Transfer Clinic?</li> <li>• Contact number of person at SVH for patients to contact in interim</li> </ul>
---	--

**4pm Finish**