



TRANSITION CARE NETWORK FOR YOUNG PEOPLE WITH CHRONIC CHILDHOOD ILLNESSES /DISABILITIES

FRAMEWORK

Last Modified in September 2013

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INTRODUCTION

Background

The Transitional Care for Young People with Chronic Childhood Illnesses Group originated from a proposal put to the Greater Metropolitan Transition Taskforce (GMTT) in 2002 for the development of a coordinated Sydney-wide network of centres interested in the management of thalassaemia. The proposal was reviewed and approved by the full GMTT committee for further investigation.

The project team including paediatric clinicians, adult clinicians and consumers commenced meeting in December 2002. It soon became evident that problems experienced by the thalassaemia group were also experienced by other young people with chronic childhood illnesses. Funding was granted and a Program Manager and 3 Transition Coordinators were appointed in 2004. In this year, GMTT became the Greater Clinical Metropolitan Taskforce (GMCT) to reflect the significant contribution of clinicians across the various programs. In 2010, GMCT evolved to the Agency for Clinical Innovation, (ACI) a Statutory body that reports to NSW Parliament. The Transition Care Network is one of 29 ACI clinical networks and reports to the ACI Board and CE via the Director of Primary Care and Chronic Services.

Stakeholder consultation revealed that there were multiple problems and issues were complex. Paediatric services tend to have forged long-standing relationships with the young people and their families or carers and in the main; the health related needs of the young people are well met. However, upon reaching adulthood and leaving the paediatric services, young people with chronic childhood illnesses and their carers often have difficulty finding out about and at times accessing, appropriate health and social services.

An inherent implication related to entering the adult health care scene is that these young people and their carers are often required to independently and autonomously navigate the health care system. Sometimes, an inability to proactively exert some control over this system results in negative health outcomes for these young people and a reliance on crisis services. Evidence indicates that when the care of the adolescent is transferred from one of the three paediatric hospitals to a multiplicity of adult hospitals and ambulatory care services, there is potential for this transfer to result in a lack of continuity of care. This reduces quality of life for the young person and their carers and results in poor health outcomes.

It has been agreed by the clinicians involved in this project that as health care providers they have primary responsibility for ensuring a quality process in the continuum of care provided to young people with chronic childhood illnesses. This framework document is an initiative to ensure the facilitation and development of continuous quality management processes through the continuum of care from paediatric to adult services.

It has also been recognised by the clinicians that the young people have expectations and responsibilities and are entitled to know and understand what these are. As a result, there is an associated document (Appendix 1), which describes these expectations and responsibilities with this Framework.

The clinicians involved in the development of this document recognise that this Framework will not work for all people, at all times. They also recognise and acknowledge that the transition process will not be deemed to have failed for individual young people or the organisation when there is variance to this Framework. The Framework focuses on the ideal targets for each transition phase and the wording reflects this focus. Users are urged when necessary, to consider interchanging the term 'generally' when reading or following recommendations in this Framework. The clinicians acknowledge that for some young people, transition may never be a fully completed process.

A primary objective of the Framework is to be sufficiently flexible for individual and local adaptation to meet the particular needs of the individual or organisation.

PURPOSE OF THE DOCUMENT

“Adolescence is a time of rapid change and complex interactions between physical, mental, emotional and social development. Young people with chronic and disabling conditions constitute a vulnerable group for whom many aspects of physical, sexual and psychosocial growth and development may be adversely affected.” (Beckett et al)

The purpose of this document is to assist all stakeholders involved in the process of transition to manage this group of young people with chronic childhood illnesses through transition, to achieve successful health outcomes and enhanced quality of life for young people and their carers/families.

The document has been developed as a generic tool, which can be utilized by all stakeholders. The document is to be used as a first point of reference for the development of all Transitional Care services, both Paediatric and Adult based, to ensure appropriate planning, preparation and management of the transition. The document will be part of a larger group of management tools to assist the process of transition, for example information packages for transition, ‘readiness’ checklists for appropriate timing of transition. Specialty groups will focus on development of extended tools which meet the needs of particular chronic disease groups.

It is hoped this document will:

1. Assist clinicians to work actively in consultation with the young person and their family/carers to define objectives which are agreed upon, measurable and achievable and that data will be collected prospectively to evaluate the process of transition.
2. Assist stakeholders to achieve the goal of planned transition undertaken early and over time in a team approach.
3. Ensure the provision of health care is uninterrupted, coordinated, developmentally appropriate and psychologically sound, resulting in minimised health problems and enhanced quality of life.
4. Result in successful engagement of adult services at an appropriate time.
5. Ensure the expectations of the young person and the team are met.

This document will provide a framework reference which can be tailored to specific needs and which ensure a quality approach to the management and planning of the transition process. This document aims to directly contribute to the ultimate goal of successful transition as determined by continuity of health care, appropriate use of health care services, maintenance of the young person’s health and enhanced quality of life by minimising admission to acute hospital beds.

ACI TRANSITION CARE
FOR CHILDREN WITH CHRONIC CHILDHOOD ILLNESSES / DISABILITIES
GENERIC GUIDING PRINCIPLES

- Transition is a planned process which is undertaken early and over time, by the paediatric health care worker/s, young person and family, with the objective of integrating into adult services by identifying and engaging adult services at an appropriate time. Planning and preparation continues in a collaborative team approach with stakeholders, in particular adult services, until transition is achieved.
- Transition planning should aim to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound and it should meet the expectations of the young person and the transition team.
- Transition planning should aim to minimise health problems and enhance the quality of life.
- Planning and preparation should be managed to appropriate and agreed timeframes.
- Planned transition should facilitate access to adult health care providers and relevant support services thus ensuring optimal use of health services.
- Transition planning should utilise a clinician and consumer designed framework, which supports a team/partnership structure approach to continuity of care achieving better outcomes for chronically ill young people.
- Transition planning should develop and strengthen clinical networks, which improve access to the best possible care.
- Successful adolescent transitional services require the support of general practitioners, community resources and non-government organizations.

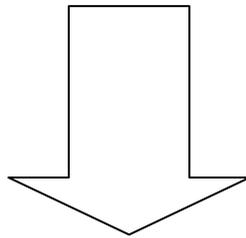
TRANSITION PLAN

For young people and their families/ carers

Specialty groups will have variance from this model and will require adjustment to address specialty needs.

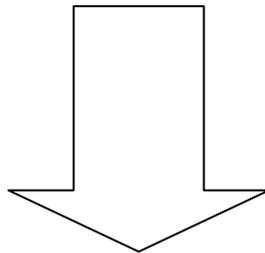
Phase One - PREPARATION

- Formal identification of Paediatric Coordinating Team (PCT)
- Planning and preparation for active transition
- Baseline Assessment of Readiness completed for and by, young person, family/carers and staff
- Identification, selection and inclusion of appropriate Adult Services



Phase two - ACTIVE TRANSITION

- Ongoing evaluation of Assessment of Readiness
- Engagement of Combined Paediatric and Adult Transition Team (CTT) in partnership with young person and family/carers
- Successful transfer to adult services



Phase Three - INTEGRATION

- Completed transfer and integration into adult services
- Quality Outcomes evaluated
- Assessment of Readiness evaluated

It is acknowledged that the expectations of the young person in transition as well as the expectations of the clinicians need to be considered if the transition process is to be successful. An Expectations document is contained in Appendix 1.

ACI TRANSITION CARE FOR YOUNG PEOPLE WITH CHRONIC CHILDHOOD ILLNESSES / DISABILITIES

DEFINING THE FRAMEWORK

Defining transition

Young people with chronic health conditions face two simultaneous transitions:

- a developmental transition (from childhood to adolescence to adulthood)
- a situational transition (from paediatric care to adult health services)

They may also have a third transition, from relative health to illness, depending on the progression of their illness. The process of transition for the young person will generally begin around age 12 to 14 and be completed in late teens. It is understood that there will be significant variance between each young person and there will be adjustment required to accommodate their specialty needs.

PHASE ONE – PREPARATION

1. Formal identification of the Paediatric Coordinating Team

The team should consist of:

- Paediatric clinicians
- Young person
- Family/carers
- Relevant others (such as advocate or youth services)

In these early stages the team will need to:

- Identify one member to become the Case Manager (if one has not already been identified)
- (Encourage the adolescent and family to) Establish links with a General Practitioner and NGOs.

The goal of transition is to provide health care that is uninterrupted, coordinated, developmentally appropriate and psychologically sound, minimizing health problems and enhancing quality of life.

2. Planning and preparation for active transition

A toolkit has been developed to assist in the planning, preparation and implementation phase for the young person. It contains examples that could be utilised, including:

- An assessment of readiness checklist for use by professionals
- A range of fact sheets on many aspects of transition for young people, including a fact sheet on frequently asked questions, differences between child and adult health services, financial issues and young people's rights and responsibilities.
- Information for parents and caregivers outlining their changing role during the transition process.

These fact sheets are available in hard copy and will be available on the transition website which will be linked to the GMCT website.

Planning and preparation should commence well in advance and before the child grows out of paediatric services. It should proceed at the young person's pace according to their physical and cognitive abilities, psychological and emotional stability, family supports and general health stability. It should be considerate of, and sensitive to, developmental age as well as chronological age.

Preparation should also include management of 'culture shock' which is experienced by the young person and parents/carers when they move from a paediatric health care model to the adult system. The standard practice for paediatric clinicians is quite different from the standard practice of adult clinicians. The resources and environment also have significant differences. The team should explain and show these differences when the young person visits the adult services. A useful reference table which highlights the differences in approach by the paediatric and adult health services is the Comparison of Components of Paediatric and Adult Health Care Delivery (Antle, B) ⁴ and is part of the Toolkit.

All young people, whatever their physical, cognitive and/or social circumstances, are confronted with similar developmental tasks in reaching adulthood:

1. The development of self-esteem and a healthy identity.
2. Emancipation from parental control to autonomous behaviour and some level of independence.
3. Formation of a sexual identity.
4. Establishing meaningful social and peer relationships.
5. Seeking suitable education or employment.

Objectives of a transition plan should include developing:

1. Understanding of their illness and how the illness impacts on their life in different settings.
2. Advocacy skills and knowledge of rights.
3. Independence and self-management skills and compensatory strategies.
4. Achievable, realistic goals which maintain confidence and self-esteem.

Success is determined by the continuity and use of appropriate health care services, by maintaining the young person's health and by enhancing quality of life.

Planning should:

➤ **Identify and address:**

- How the illness currently affects the person
- What issues arise as a result of the illness
- How it is currently managed
- How it may affect the young person in the future
- What the young person's concerns are (e.g. discrimination, limitations of future activities, sense of disempowerment, school and learning problems & dissatisfaction with appearance)
- Health and medical needs
- Mental health
- Psychosocial needs
- Education
- Environment
- Location of adult facilities and services
- Activities of daily living
- Developmental, environmental and lifestyle issues for young people (e.g. drug, alcohol & substance abuse, sexuality).
- The need to be seen as normal and to undertake age appropriate tasks

➤ **Consider the following elements:**

- Acknowledging the young person as an individual
- Progressing responsibility for self-management & independence, including knowledge of rights & career options & decisions about disclosure of the illness, including disclosure to the young person
- Identifying partners in transition

3. Baseline assessment of readiness

As part of the planning process, Paediatric and Adult clinicians need to undertake an assessment of readiness of the young person, their family or carer and the adult and paediatric services, in consultation with the young person and their parents or carer.

Develop an Assessment of **Readiness Checklist**.

The Assessment of Readiness Checklist should:

- describe the discrete components for transition education and preparation and the progression of transition goals and outcomes
- model 'normalised' adult transition (it is safe to assume that typical life experiences have the same importance and value for all adolescents)
- be developmentally staged across the range of years and according to 'average range' have markers for normal expectations.
- be time-framed
- include readiness checks for the paediatric and adult clinicians as well as the parents/carers
- include a Comparison of Components of Paediatric and Adult Health Care Delivery
- be a living record of the transition process which facilitates the individual plan which can be assessed on the individual's merit and according to their own variables.

The Readiness Checklist should be considerate of & include the following:

- Developmental age / Chronological age sensitive
- Psychological needs
- Physical needs
- Self esteem
- Social needs
- Educational status and needs
- Self advocacy
- Understanding of the illness
- Decision making
- Self-management
- Level of independence
- Behaviour (including consideration of adolescent behaviour in addition to any other behaviours)
- Emotional needs
- Maintain own health record
- Continuing education
- Career goals
- Guardianship issues

4. Identification, selection and inclusion of appropriate adult services

When identifying and selecting adult services the following need to be considered:

Adult facilities

- Consider location as proximity may be an issue requiring management

- Consider safety management, as some facilities and services may be better equipped and able to deal with developmental, behavioural and physical problems.
- Investigate resource issues - staff and environmental that may be relevant to the young person
- Consider strategies that foster a friendly environment
- Actively manage the impact of the shock
- Ensure continuity of follow-up
- Consider staff opportunities for further training
- Provide resources & education on youth health & development
- Adult facilities and clinicians should consider the expectations of young person through the transition period. (See Appendix 1)

General Practitioner

- The team must keep the GP informed of all health matters
- The team may need to provide additional support when a GP changes

NGOs and Community Supports

- Specialty specific
- Religious organisations
- Voluntary organisations

Schools / Tertiary Education Facilities

- Identify and establish lines of communication with appropriate staff
- Identify environmental issues for management

PHASE TWO - ACTIVE TRANSITION

1. Combined Transition Team of paediatric and adult services is engaged in partnership with the young person and their parents/ carers.

Strategies should:

- i) Be best practice and evidence based
- ii) Be outcomes focussed
- iii) Engage stakeholders and
- iv) Include appropriate multidisciplinary team members

The team comes together to decide on an implementation plan for the assessment of readiness. Negotiations are made to determine roles of team members in supporting the young person and their family/ carers.

2. Successful preparation for transfer to adult services

2.1 Planning and preparation by the Combined Transition Team (CTT) in active transition should be based on:

- Objectives which have been identified in the Assessment of Readiness Checklist and planning and preparation issues still under management by the Paediatric Coordinating Team – thus ensuring seamless continuity of transition.
- Specific developmentally appropriate strategies, considering educational status of the young person.
- Activities that facilitate the development of skills and the acquisition of information necessary for independence.
- Development of compensatory strategies.
- Ensure a support system composed of family, peers, professionals, personal care attendants, other organisations and members of the young person's vocational,

religious and community resources, is in place to assist through the transition process and continue links into the future.

CTT planning and preparation should incorporate:

2.1.1 Financial management and Affordability

- Investigate what costs are likely to change for medical care, pharmacy, equipment and other consumables & who pays
- Investigate changes to transport costs
- Investigate Centrelink & Medicare/Private Health Insurance cost changes & responsibilities
- Eligibility for carer payments and ongoing carer costs

2.1.2 Mentoring opportunities

- Mentoring by adults with specialist skills, same illness, similar experiences etc
- Peer programmes – Big Brother/Big Sister

2.1.3 Expanding support network

- Investigate appropriate linkage to social supports for the young person and family
- Investigate cross-government services such as Centrelink & Medicare for information

2.1.4 Legal aspects

- Knowledge of rights, including anti-discrimination laws and other appropriate laws
- Guardianship issues

2.1.5 Investigate environmental requirements

- Access – identify internal & external issues for management
- Modifications required to manage a new environment
- Impact of climatic changes

2.1.6 Sexual Health & Education

- Age appropriate information
- Managing generic health issues
- Managing specialty health issues

2.1.7 Healthy Lifestyle

- Healthy diet
- Leisure activities

2.1.8 Training & Job opportunities / Tertiary education

- Exploring career opportunities

2.2 Successful preparation of the young person

2.2.1 Initiated by the young person

- Develop goal directed and time-framed strategies from the Assessment Checklist with the CTT
- Explore resources available to develop skills and knowledge negotiating healthcare system (see Toolkit for resources)
- Know expectations of the transition process, and individual rights and responsibilities

2.2.2 Provided or facilitated by members of the CTT

- Provide information about expectations of the transition process, rights and responsibilities
- Ensure young person has a good understanding of their specific condition(s)
- Address normal puberty issues

- Address issues specific to the particular illness/disorder/disability
- Provide the young person with sufficient knowledge, skills and/or supports needed to promote healthy behaviours and to prevent or reduce the incidence of risky behaviours and secondary disabilities
- Provide information and ensure understanding about how the health care system works (appointments, scripts, referrals etc) interactions with health professionals, their own follow-up & therapy requirements
- Discuss the importance of therapy compliance
- Show how to maintain personal health care record
- Provide continuing education opportunities
- Self advocacy and negotiation
- Provide the opportunity meet the Adult Services at either the adult or the paediatric setting

2.3 Successful preparation of the paediatric clinicians

- Use Assessment of Readiness as a guide to determine gaps in individual knowledge and skill, and in service readiness (see Toolkit)
- Explore resources available to develop skills and knowledge in working with young people (see Toolkit for resources)
- Develop goal directed time-framed strategies which facilitate transition and transfer to adult clinicians, as a member of the CTT
- Be aware of relating to the young person as an individual, encourage questions and acknowledge their capacity for making choices of their own
- Expect to plan future health care goals together including an individualized health care plan
- Should meet with the Adult Services at either the adult or the paediatric setting
- Be aware of the preparation required by the parents for the young persons transition and facilitation of this preparation as required

2.4 Successful preparation of the adult clinicians

- Use Assessment of Readiness as a guide to determine gaps in individual knowledge and skill, and in service readiness (see Toolkit)
- Explore resources available to develop skills and knowledge in working with young people (see Toolkit for resources)
- Develop goal directed time-framed strategies which facilitate transition and transfer to adult clinicians, as a member of the CTT
- Be prepared to address specific specialty issues
- Be aware of relating to the young person as an individual, encourage questions and acknowledge their capacity for making choices of their own
- Should meet with the paediatric services at either the adult or the paediatric setting

2.5 Successful preparation of parents/carer

- Use Assessment of Readiness as a guide to determine gaps in individual knowledge and skill, and in service readiness (see Toolkit)
- Explore resources available to develop skills and knowledge in working with young people (see Toolkit for resources)
- Facilitate parents planning and guide them in their future role in relation to the young person
- Parents to prepare the young person for independence at appropriate stages
- Parents to facilitate financial management requirements and planning for the young person
- Parents to have information provided to them about Adult services
- Consider what strategies of supports must be implemented to meet the parent's needs
- Explore respite options and other services following transition

PHASE THREE – INTEGRATION

1. Completed transfer and integration into Adult services

Transition is complete and integration is achieved when appropriate adult services have been successfully engaged and management is transferred from the paediatric services. At that time the young person will have achieved an acceptable balance of independence and support.

As the young person clinicians and parents reach the determined goals of the planned transition, the adult services will move into the roles formerly managed by the paediatric services, as negotiated in the transition process.

Successful planning and preparation for transition will result in improved quality outcomes for young people.

2. Quality Outcomes evaluated

Improved quality outcomes will be evident in:

1. Maintenance of continuity of health care
2. Reduction in secondary disability and serious complications
3. Optimal use of health care resources
4. Development of life-long skills.
5. Satisfied team

3. Assessment of Readiness Evaluated

Evaluation should focus on surveys and information from the following (see Toolkit):

1. The clinicians
2. The young person
3. The carers
4. The CTT

It is necessary that the CTT agree on a future date (eg six months, twelve months) to discuss and evaluate the long term success of the transition planning.

Glossary of Terms:

- Case Manager – Person who oversees and coordinates the young persons' health care. Responsibilities may alter over time during the Transition Process.
- Contract – A negotiated agreement.
- Readiness – Relates to the young person, the family, paediatric and adult services. Assessment of the willingness and capacity as well as the current level of functioning of the young person, to prepare for and undergo transition. It also involves the willingness and capacity of the family, paediatric and adult services to provide appropriate level of support, planning and care for the young person.

APENDIX 1

EXPECTATIONS: THE PROCESS OF TRANSITION

The fundamental rights of the individual must be recognised (Ref: The Universal Declaration of Human Rights and The Declaration of the Rights of the child).

It is important to acknowledge that the young person involved in the transition process is the prime focus of this process. The involvement and recognition of the young person is fundamental and should be continuously acknowledged and respected. The expectations of each the young person and the clinician should be jointly discussed and acknowledged. Clinicians have a responsibility to provide young people with information of their entitlements to assist them in assuming responsibility for themselves. The young person has an obligation to start taking responsibility for themselves, their actions and decisions, so far as they are able. They should be provided with support and skill development opportunities to enable this assumption of responsibility. Decisions should be made after careful consideration of the information provided and clarifying the information when necessary to gain full understanding, including the consequences of actions.

Each young person involved will vary in developmental stages, intellectual ability and individual capacities. If the young person does not have the capacity to make decisions they require an advocate. It should be noted that the following expectations will not be appropriate to all young people. They should be used as guidelines and adjusted accordingly.

Every young person in transition will expect the following, delivered in a way that is appropriate to his/her development.

To:

- be respected and treated fairly.
- be informed about their medical condition(s), planned treatment and any side effects or complications.
- be included in decisions made about their future care and management.
- have shared responsibility for care and management with the health care workers, the family and any other support networks.
- have control of their personal care.
- have their social, educational and vocational needs and wants acknowledged and facilitated.

- have access to information regarding their sexual development, relationship guidance and sexual exploration.
- If desired have an appropriate support person/people
- have an advocate, if desired.
- have access to an appropriate interpreter.
- have access to health records as per the facility guidelines.
- have access to spiritual or religious guidance.
- have cultural beliefs and traditions respected and be able to follow these beliefs and traditions when possible.
- have confidentiality and privacy respected unless legislation requires otherwise.
- be advised there is a process for complaints and grievances and have access to the procedures.
- feel confident and safe discussing any concerns with the transition team.
- have the process of transition treated as a normal phase of lifelong health care.
- have the transition as a continuous process, which is guided by their needs in a holistic manner.

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Christopher Webber Sydney Children's Hospital, Paediatric Emergency Physician & Consultant Physician
Julie Adamson John Hunter Children's Hospital, Paediatrician
Elisabeth Hodson The Children's Hospital Westmead Head, Department of Nephrology
John Dwyer Prince of Wales Hospital Professor of Medicine / Director of Medicine
Chloe Blanch Consumer Representative
Marea Howe Consumer Representative
Allan James Shellharbour/ Wollongong Hospital Paediatrician
Kidest Nadew Sydney Children's Hospital CNC HIV Services

Jan Steen GMTT Project Manager - December 02 - April 03

Charlotte Roberts GMTT Project Manager- April – July 03

Sally Nicholson GMTT Project Manager – July 03 – May 04

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Members of the ACI Transition Executive

Lynne Brodie ACI Transition Care Network Manager

ACI Transition Care Coordinators: Patricia Kasengele, Angie Myles, Sarah Ryan