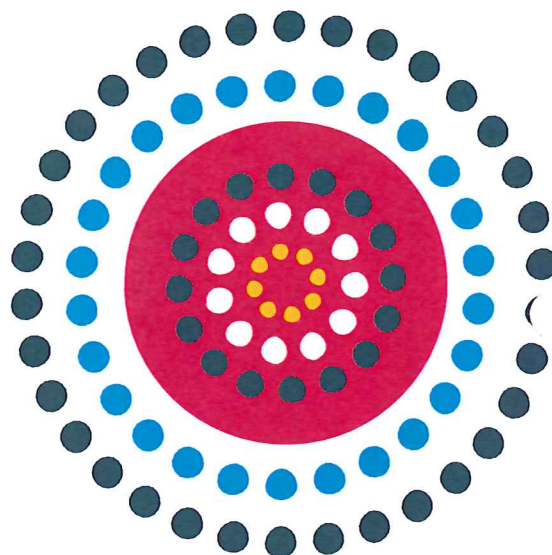
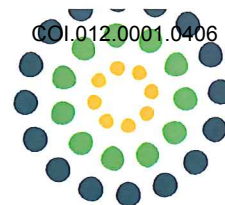


Key Principles

for Transition of Young People
from Paediatric to Adult Health Care





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Transitions principles are vital for any health professional working with young people as they underpin the practices required for successful transition.

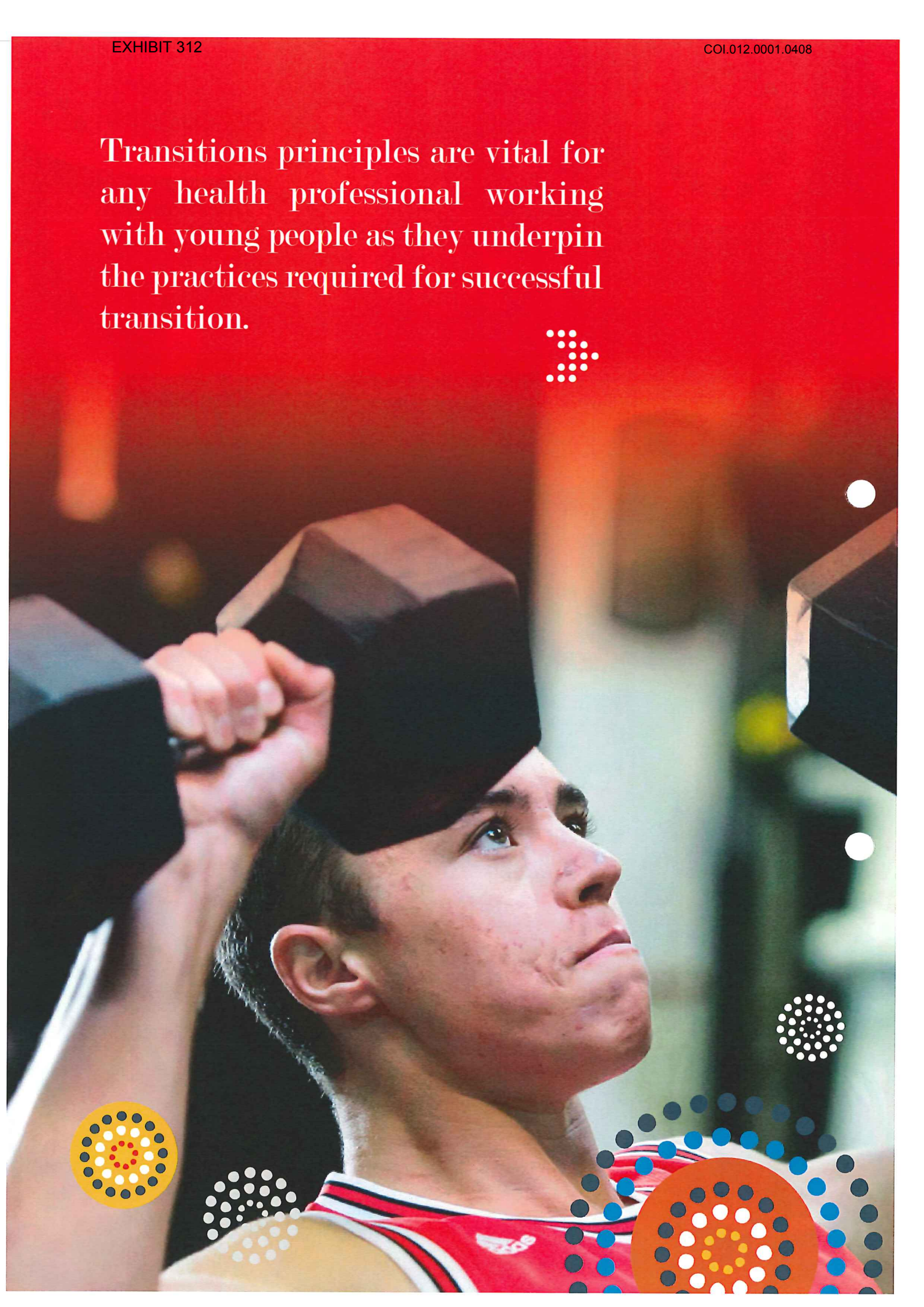
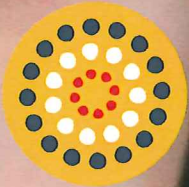


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Introduction

In 2009, there were nearly 4 million young people aged 12-24 in Australia (2.0 million males and 1.9 million females) representing 18% of the total population.¹ Approximately 12% reported at least one chronic condition/disability.² Within Australia and globally, there is an increasing burden of chronic conditions. Young people with chronic conditions arising in childhood such as congenital cardiac disease, spina bifida and muscular dystrophy are contributing significantly with over 90% now estimated to survive into adulthood.³

As a consequence of this increase in survival, adolescents are transitioning at an increasing rate from paediatric services into mainstream adult services which are often ill equipped to meet their needs. Transition is defined as *'the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems'*.⁴ There is increasing pressure to ensure a seamless transfer and transition from children's to adult health care services in order to achieve improved health outcomes for young people.

Sawyer et al⁵ report increasing evidence that young people with chronic conditions are doubly disadvantaged when they leave paediatric care because they *'engage in risky behaviours at a rate at least similar if not higher than healthy peers, while having the potential for greater adverse health outcomes from these behaviours'*. For specific conditions such as diabetes there is increasing evidence of poorer outcomes for young people who may disengage from health services.⁶ Indicators such as poor glycaemic control have been demonstrated along with increased rates of emergency presentations in hospitals and diabetes related complications.^{7,8} There is also evidence that providing appropriate transition services can impact positively on the young person's ability to manage their health and improve specific indicators such as HbA1c levels.⁹

Transitions principles are therefore vital for any health professional working with young people as they underpin the practices required for successful transition. Further, they guide and inform a health professional's practice and act as the foundation for transition work.



Development of the Principles

The principles for the transition of young people with chronic conditions from paediatric to adult care have been developed by the Agency for Clinical Innovation (ACI) Transition Executive Committee and Trapeze, The Sydney Children's Hospitals Network (SCHN), for use in the NSW Health system. The age range focuses on those aged 14 - 25 years. Young people who are diagnosed later in adolescence with a condition that is likely to be chronic such as stroke, cancer or brain injury should commence preparation for transition at the earliest possible stage.

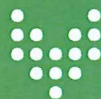
The principles are evidence-based and aim to promote best practice for health professionals involved in caring for young people during transition. However it is recognised that despite agreement about the importance of effective transitional care, there is little evidence to inform best practice about both the process and what constitutes effective transition.¹⁰ Moreover, evidence when it does exist is often of poor quality.¹¹

These principles are based on the evidence that has been evaluated in systematic reviews undertaken by Crowley, Wolfe Lock and McKee in 2011,¹² and Kime, Bagnall and Day in 2013.¹³ The evidence correlates with that cited in key documents such as the NSW Youth Health Policy 2011-2016,¹⁴ the Transition Guidelines developed

by the Royal Australasian College of Physicians,^{2, 15} and the Western Australian Paediatric Chronic Diseases Transition Framework.¹⁶ The ACI Transition Care Network and Trapeze, SCHN believe that the implementation of, and adherence to, evidence-based principles will considerably improve the care and management of young people with chronic conditions transitioning from paediatric to adult health care leading to:

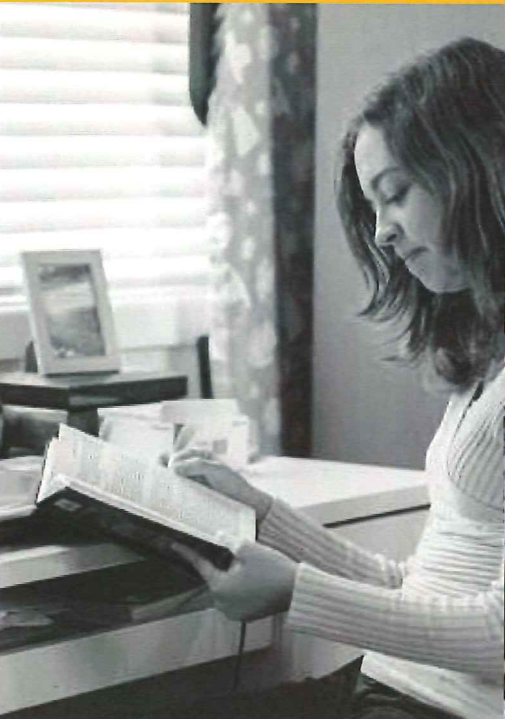
- better functional outcomes such as increased adherence, improved self-management and knowledge of their condition, and improved wellbeing;
- better access to appropriate health services for young people with a chronic condition;
- improved morbidity and mortality rates; and
- a reduction in avoidable hospital admissions.

It is a reality that some young people will be unable to benefit from the principles outlined as they may never achieve independence and will require the support, often lifelong, of parents/carers. While many of the principles can be adapted to take special needs into account, it is acknowledged that for many young people and their families/carers there are added challenges that are not addressed in this document.





Key principles of care for young people transitioning to adult health care.



A Systematic and Formal Transition Process

1

A systematic and formal transition process is required. This should be underpinned by formal guidelines and policies outlining the transition process.



Early Preparation

2

Transition is a process not an event. Education on transition and empowerment around self-management will commence with the young person at the age of 14.



Identification of a Transition Coordinator/ Facilitator

3

A designated Transition Coordinator/Facilitator from the young person's paediatric and adult specialty teams should be identified to coordinate the transition.



Good Communication

4

Communication processes and tools will support person-centred care for the young person throughout their transition journey. Openness, transparency, collaboration and a willingness to work together underpins all good communication.



Individual Transition Plan

5

All young people should have an individualised transition plan which focuses on all aspects of their life.



Empower, Encourage and Enable Young People to Self-Manage

6

Responsibility for decision-making should be increased gradually and adolescent friendly transition services should be put in place. Where the young person has complex needs, it is particularly important to involve their family/carer.



Follow up and Evaluation

7

Follow up may be required for several years to ensure that young people have engaged effectively with adult health care services. Evaluation of the transition process must be undertaken to inform future planning and policy.



PRINCIPLE 1

A Systematic and Formal Transition Process



In order for young people, their families/carers and clinicians to be fully aware of what transition involves, a systematic and formal transition process is required. This should be underpinned by formal guidelines and policies outlining the processes.

1.1 Applying the principle in practice

- All health services working with young people with chronic conditions throughout NSW should have a formal transition process which can include, but not be limited to:
 - transition guidelines and policies;
 - clear referral pathways for transition of young people;
 - a youth focus for all facilities managing adolescents; and
 - a local transition committee which includes clinicians, young people and all relevant professionals. This may involve expanding existing committees to include young people rather than forming a new committee.

1.2 Evidence-base

- 'The overarching theme from the findings is the requirement for a formal transition process for young people with long-term conditions'. A transition programme should be embedded in service delivery with a written protocol/roadmap detailing the steps involved'.¹³
- 'NSW Health needs to ensure that young people can identify and access the information and support services they need [for transition]'.^{14, 15}



- 'The health needs of young people are often poorly met because they do not comfortably fit anywhere... youth friendly services are required in all health settings'.¹⁶
- 'Institutional and management support must be assured at both ends of the transfer chain. Casual agreements between doctors, although easy to set up are prone to failure'.¹⁷

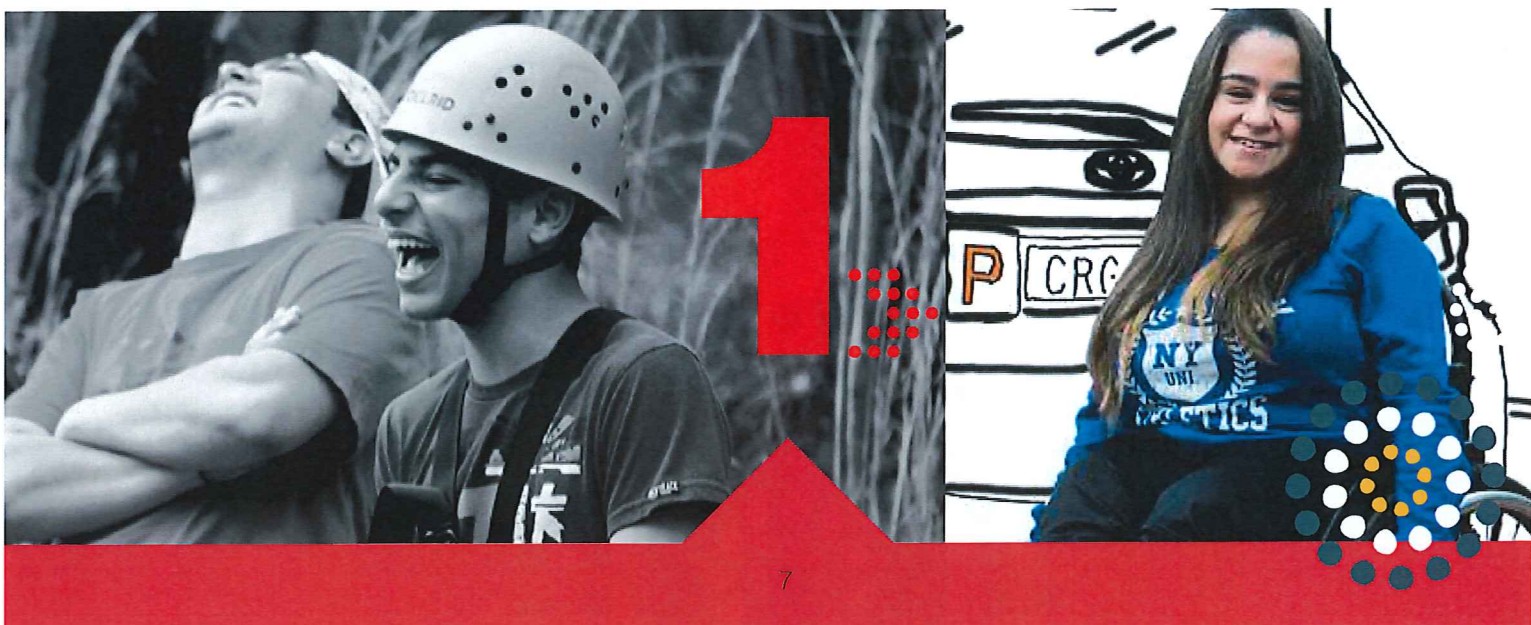
1.3 Quality measures

System measurements

- All health services who manage young people with chronic conditions and disabilities aged 14 - 25 years to have local processes/structures that focus on the needs of young people with chronic conditions/disabilities
- All health facilities who work with young people to have a transition policy developed in consultation with young people
- Audit of transition processes conducted yearly

Patient measurements

- Surveys of young people demonstrate awareness of policies and processes
- Young people represented on above committees



PRINCIPLE 2

Early Preparation



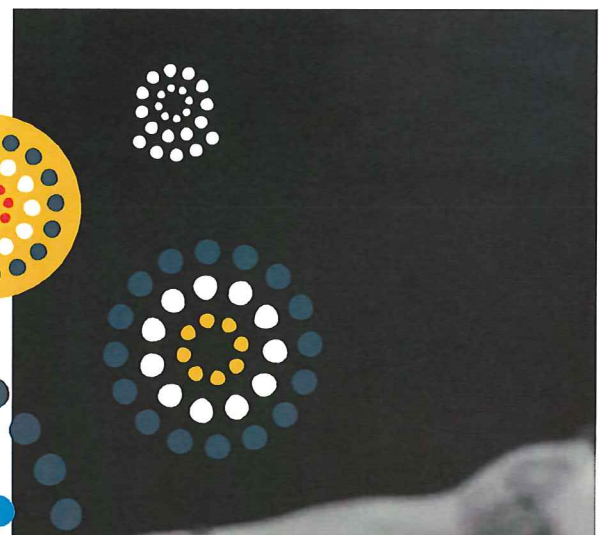
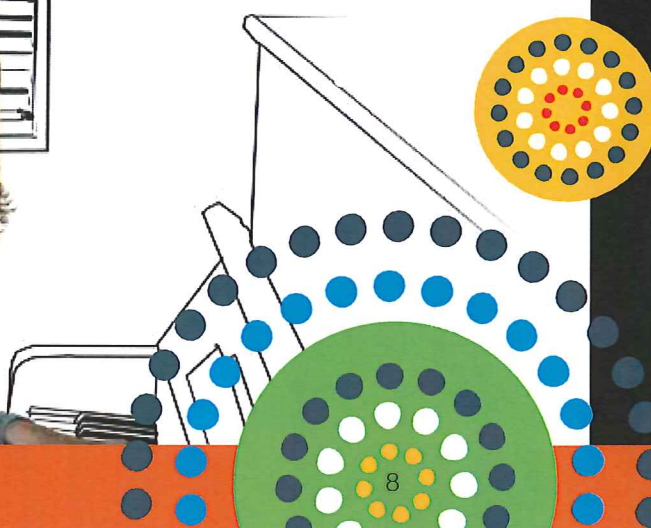
Transition is a process not an event. Young people aged 14 and over with a chronic condition / disability will be identified in the paediatric setting, and education on transition and empowerment around self-management that is developmentally appropriate will be undertaken as early as possible with the young person and their parent/carer.

2.1 Applying the principle in practice

- All young people aged 14 and over should be identified for transition planning and referred to a specialist transition service so that transition can be planned. For young people known to SCHN, referrals are to be made to Trapeze. For all other paediatric settings, a member of the clinical team needs to be identified who will refer to the Transition Care Coordinators (TCCs).
- Other specialist groups are also important in facilitating transition. An example is the Spina Bifida Adult Resource Team (SBART), the key organisation for young people with Spina Bifida in NSW. Young people with Spina Bifida should also be referred to them.¹⁸
- Easy to read information appropriate to the different stages of transition should be available in both electronic and hard copy. This information will cover aspects such as the differences between children's and adult health services, the transition pathway and process, and transition checklists. Education sessions can be organised through Trapeze and AGI on an individual or group basis for both young people and their families.
- Increasingly apps and social media are being widely used by young people with some reports suggesting social media use upwards of 99%.^{19, 20} Health services are therefore encouraged to develop and offer social media as a transition tool for young people.

2.2 Evidence-base

- 'Preparation must begin well before the anticipated transfer time-preferably in early adolescence...'¹⁷
- 'Timing must depend on the developmental readiness and health status of the individual adolescent as well as the capabilities of the adult providers'.²¹



- 'On the paediatric side, the process of transition of care needs to be started early by systematically discussing developmental stages and age specific challenges with all patients and families'.⁸
- 'Transitional care should start early and strategies should promote uninterrupted, comprehensive and accessible adult care'.²²
- 'The model least likely to meet young peoples' needs sees transition as a single transfer event to an unfamiliar clinic with completely new adult health care professionals, whose views on the management of the condition are different from their previous practitioners' views'.¹³

2.3 Quality measures

System measurements

- All patients aged 14 years and over with chronic conditions/disabilities be identified and referred to specialist transition services, namely ACI, Trapeze and where relevant, SBART
- Education sessions are available to individuals/groups
- Resources are available in paper and electronic format
- Referrals are monitored and tracked
- Transition readiness checklist is completed once young person is identified as requiring transition

Patient measurements

- Satisfaction surveys of young people
- Pre and post education questionnaires



PRINCIPLE 3

Identification of a Local Transition Coordinator/Facilitator



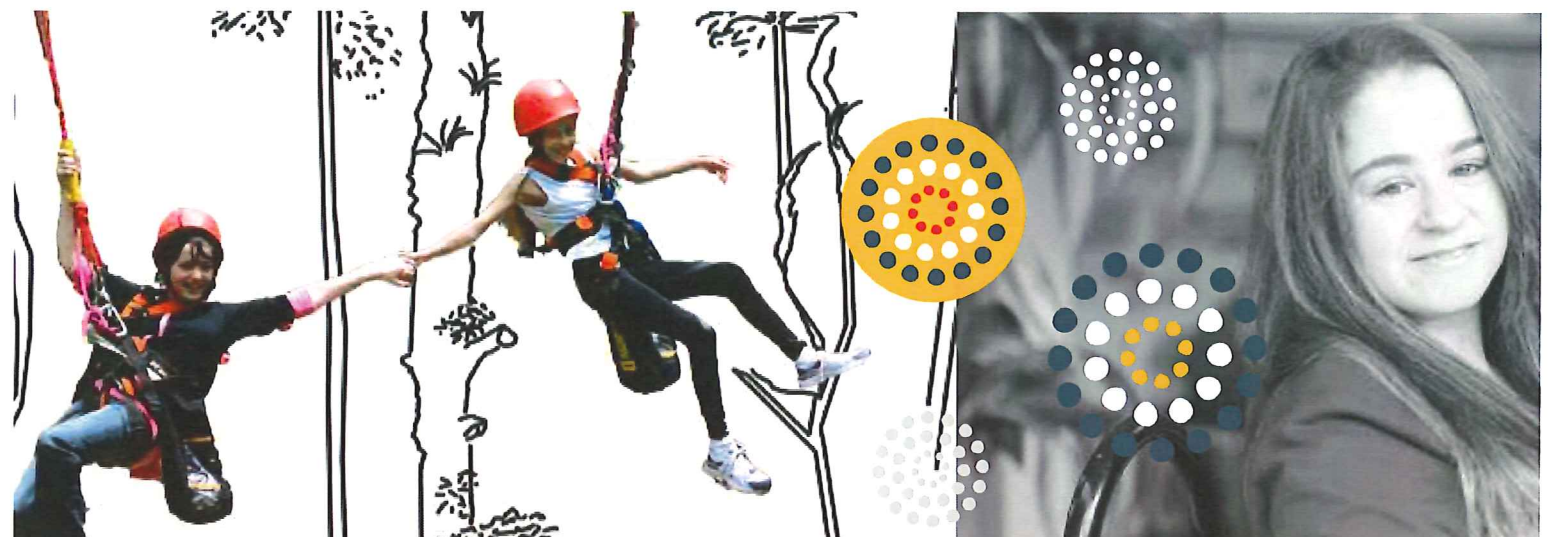
A planned and coordinated transition is necessary for young people and this can be achieved by identifying a transition coordinator/facilitator within the young person's health facility.

3.1 Applying the principle in practice

- All facilities who manage young people with chronic conditions should identify a person within the young person's clinical team to act as a transition coordinator/facilitator. Time needs to be designated so that this person can perform their role in facilitating transition.
- This person may be any member of the multidisciplinary team. Their role is to identify young people, ensure that they receive education packages and are referred to appropriate services such as Trapeze and ACI TCCs.
- Young people should have a named contact within both children's and adult services.
- All young people should have a General Practitioner (GP) identified prior to transfer. In some cases the GP may take the role of coordinator.

3.2 Evidence-base

- 'Transition is generally optimised when there is a specific health care provider who takes responsibility for helping the adolescent or young person and his family through the process'.²
- 'A dedicated transition worker can have a positive impact in most health care settings, and young people should have a named contact within both children's and adult services'.^{23, 24}



- 'Ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition...in partnership with their health professionals, the young person and their families'.³
- There should be a lead professional to support young people and their families through transition.^{24, 25}

3.3 Quality measures

System measurements

- A coordinator from the lead clinical team is allocated to every young person by age 14
- The clinical team refer to Trapeze for young people known to SCHN and ACI for outside SCHN from the age of 14
- Numbers of referrals made by each clinical team

Patient measurements

- Patient satisfaction with process
- Young person and clinical team can name their coordinator
- Young person is engaged with Trapeze and/or ACI



PRINCIPLE 4

Good Communication and Shared Responsibility



Communication processes and tools will support person-centred care for the young person throughout their transition journey. Openness, transparency, collaboration and a willingness to work together underpins all good communication.

4.1 Applying the principle in practice

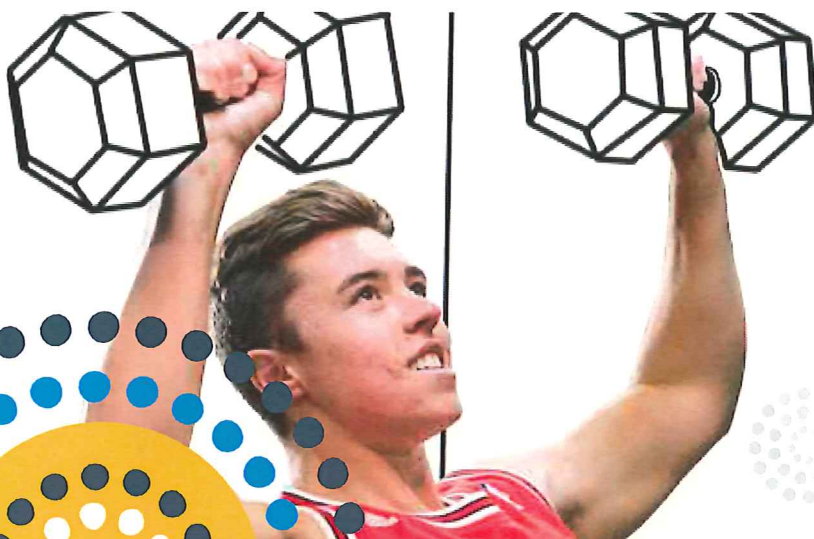
Good communication between all relevant parties is essential to effective transition, particularly between the young person and their family with their paediatric and adult health professionals, and the young person's GP.

Aspects of good communication include:

- identification of all those relevant to the transition process;
- openness, transparency, collaboration, and a willingness to work together;
- adolescent friendly language;
- establishing systems for joint collaboration and communication including technology based and telephone communication;
- comprehensive written communication – standardised templates available from Trapeze or ACI can be adapted for each young person;
- joint paediatric/adult clinics prior to transfer;
- specific transition clinics e.g. young adult clinics; and
- respecting privacy and confidentiality of young person.

4.2 Evidence-base

- 'Where to begin... Begin with communication, have heartfelt conversations with your patients, dialogue with other treatment providers and query your colleagues. Transform these conversations into action...'²⁶
- 'Whether or not a transfer of care occurs, successful transition requires communication and collaboration among primary care specialists, sub specialists young adult patients and families'.³
- 'The most commonly used strategies used in successful programs were patient education and specific



transition clinics (either jointly staffed by paediatric and adult physicians or dedicated young adult clinics within adult services'.¹²

- Partnerships between paediatric and adult specialist health services, primary health carers, school and community health care professionals, patients and their parents/ carers are needed to ensure a collaborative and consistent approach to transition.¹⁶
- 'Systematic review suggests that interventions using electronic media can improve health/safety behaviours in young people'²⁷
- Socially, the current generation of young people has different ways of communicating than previous generations, having grown up with access to mobile phones, the internet and email and the emergence of social media.^{20, 28}
- Joint care management is undertaken for different reasons and to varying levels in different areas of practice. In some areas involvement is approached on a case-to-case basis depending on the needs of the young person, while in others it involves shared clinical management through either joint clinics or integrated teams.¹¹

4.3 Quality measures

System measurements

- Demonstrated communication strategy with identification of all relevant participants including inter- and intra-agency coordination
- Detailed transition discharge summary available and shared with all relevant parties
- GP receives discharge summary and outpatient letters
- Joint transition clinics or specific transition clinics

Patient measurements

- Young person and family have access to their health information and are aware of all health professionals involved in their care



PRINCIPLE 5

Individual Transition Plan



All young people should have an individualised transition plan which focuses on all aspects of their life.

5.1 Applying the principle in practice

Individual transition plan is developed in partnership with the young person and their family/carer from the age of 14.

This is best done by the clinical lead transition coordinators



Young person is referred to Trapeze for SCHN, and to ACI for those outside SCHN

Make sure young person has a copy of the plan



ACI Transition Care Coordinator or Trapeze follows up post transition

Trapeze and ACI monitors, implements and revises transition plan

5.2 Evidence-base

- Transition planning should be regarded as an essential component of care quality in adolescent-oriented services.^{25, 26, 29, 30}
- A written transition plan can help parents to teach their adolescent how to carry out an increasing number of health care related tasks and activities.^{31, 32}
- Transition planning must be youth focused within the context of the family.³³



- 'A transition plan needs to be tailored to the individual, incorporating a holistic approach that takes into account the medical and psychosocial needs of the individual. Special consideration should be given to adolescents with cognitive or developmental delays'.³⁴

5.3 Quality measures

System measurements

- Individual transition plan developed, implemented, and updated regularly
- Individual transition plan accessible and visible to young person and all relevant health professionals
- Young person referred to Trapeze, ACI and other specialised service such as SBART

Patient measurements

- Young people are involved in the development of their plan and are given a copy
- Young person has an allocated support coordinator from Trapeze or ACI



PRINCIPLE 6

Empower, Encourage and Enable Young People to Self-Manage



The process of teaching young people to self-manage should be carefully planned, adolescent friendly and developmentally appropriate. Responsibility for decision-making should be increased gradually, and the process should be discussed and accompanied by formal documentation covering details of clinical care, a record of their transition assessment undertaken by Trapeze or ACI, goals, and should include any inter-agency agreements.

Where the young person has complex needs, or will be unable to manage their care independently, it is particularly important to involve their family/carer.

6.1 Applying the principle in practice

Person-Centred Care

- Baseline health knowledge assessed
- Self-management needs identified
- Specific condition related transition groups
- Individual plan developed for education



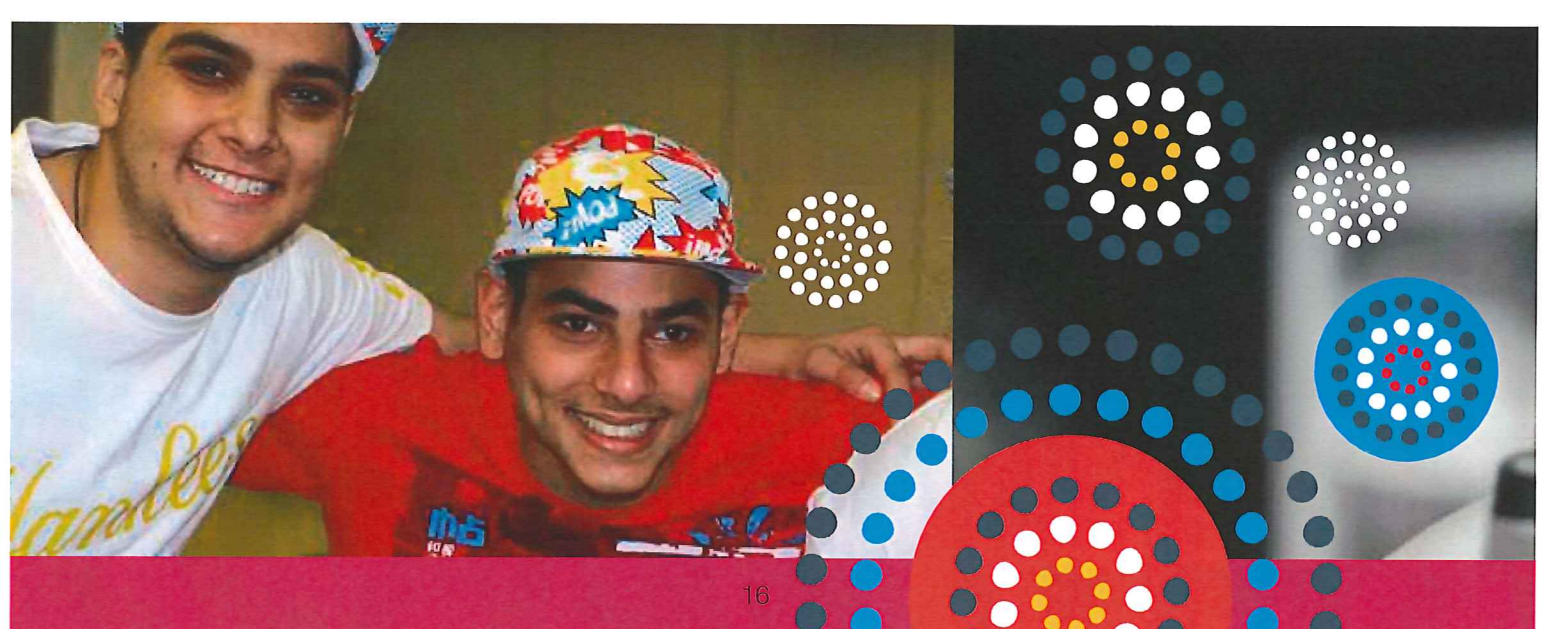
Tools

- Transition care information pack
- Transition readiness checklist
- Health coaching
- Checklists
- Apps/Social Media
- Forums
- Support Groups
- Case management services



Follow up / review

- Regular follow up, monitoring and evaluation
- Ongoing assessment when required
- Review when change occurs



6.2 Evidence-base

- 'Learning self-care skills is an important way to enhance self-esteem and autonomy and to empower the adolescent to become a responsible individual as she or he gets older'.^{17, 29, 35, 36}
- Young people expressed the need for patient choice and control, a need for independence and being more responsible for self-management.^{37, 38}
- 'Encouraging young people to develop as much independence as possible, both from their families and health care staff, will help bridge the gap to adult services and help them to make informed decisions about their own care'.³⁹
- 'Patients who were more knowledgeable about their condition were more likely to respond to providers' questions themselves and had more understanding of the implications of transition to adult care. Patients who were able to explain their diagnosis in both lay and medical terms appeared to be more confident. They communicated directly with providers instead of using their parents as a proxy and were self-assured in their ability to take care of themselves'.^{23, 40}

6.3 Quality Measures

System measurements

- Health coaching programs and self-management tools available to encourage independence
- Condition specific education transition groups

Patient measurements

- Pre and post health education surveys on knowledge, confidence, readiness
- HbA1c levels, acute and chronic complications, clinic attendance rates, self-management skills, disease specific knowledge and rates of screening for complications, and reduction in unplanned hospital admissions



PRINCIPLE 7

Follow up and Evaluation



Follow up may be required for several years to ensure that young people have engaged effectively with adult health care services. Evaluation of the transition process must be undertaken to inform future planning and policy.

7.1 Applying the principle in practice

Young person is referred to Trapeze for those known to SCHN, and to ACI for those outside SCHN.

Young person is referred to coordinator in the adult health system



Young person is tracked for as long as they require support up until the age of 25



The opportunity exists for the young person to re-engage with the transition support program once they have exited. They can also be connected to other support programs once they reach age 25



Following transition, feedback on the young persons' progress is provided to paediatric providers and to adult providers where transition has not been successful

7.2 Evidence-base

- 'Support needs to be provided to youths for 6-12 months after they make the transition to adult care with a policy in place for those youths who fail to make a successful transition. Monitoring and evaluation of patient outcomes after transition is needed.'⁴¹



- Constant assessment of how the process is going with emphasis on young patients being treated at adult-oriented services must take place for some time after the transition has been completed.⁴²
- 'An evaluation of the effectiveness of transition is required'.^{22, 25, 43, 44, 45}

7.3 Quality Measures

System measurements

Young people are tracked electronically for a minimum of 12 months post transition
Evaluation is undertaken of the transition process

Patient measurements

- Surveys of young people are conducted 6 and 12 months post transfer
- Check that the young person is engaged with a GP
- Check that the young person is engaged with adult health services



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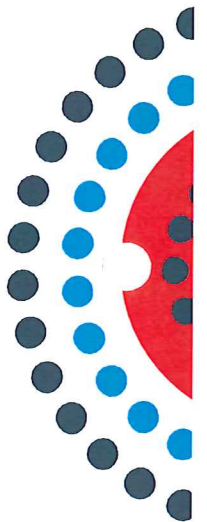
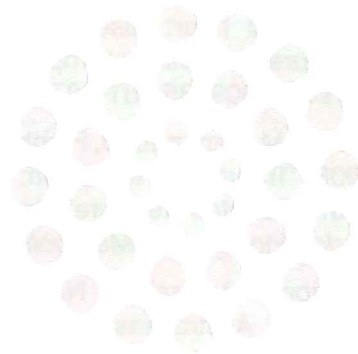
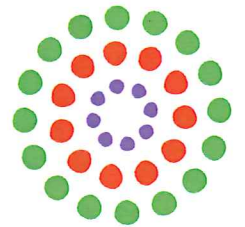
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