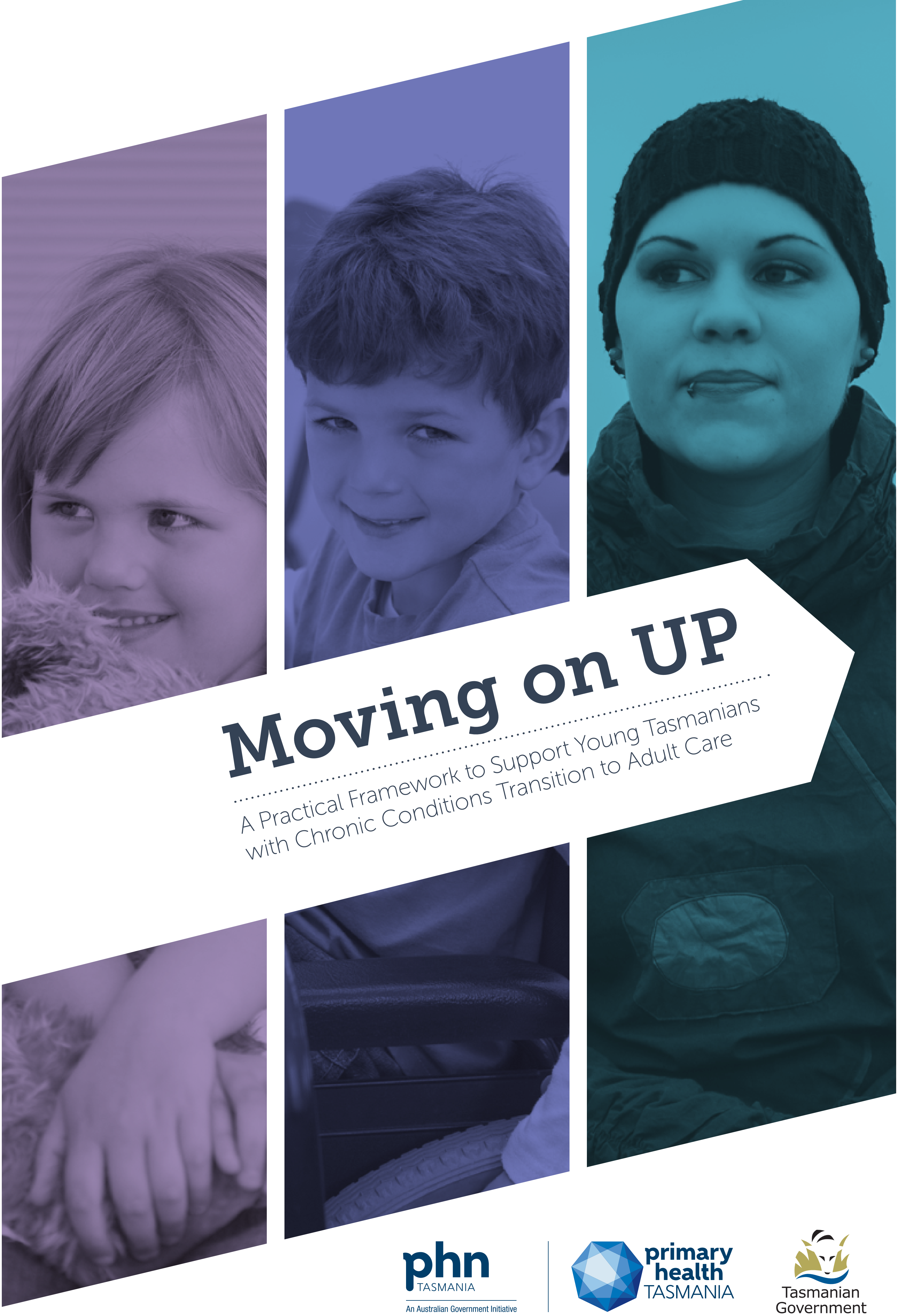

Moving on UP

A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care

phn TASMANIA
An Australian Government Initiative

primary health TASMANIA

Tasmanian Government

Foreword

Going through adolescence is hard enough and likely more so if living with a chronic condition. It is a time of vulnerability as there are many things for the individual to sort out – social pressures, mental health, drugs, emerging sexuality, educational decisions, puberty, a growing intellect and deeper level of thinking, self-consciousness, and perhaps increased awareness of what the differences and limitations are in having a chronic health or developmental condition. At the age of 18 years, the move away from trusted wonderful paediatricians, those with whom the young person and their family have been with from the start, through the diagnosis and coping, through to treatments and management of ups and downs of the chronic condition, predisposes to a real vulnerability on emotional and physical health levels. These changes coupled with a completely differently organised adult health service structure can amplify the risk of unnecessary suffering and stress.

A considered and well-planned transition process goes a long way to alleviating some of the stress. *Moving on Up–A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care* is a marvellous initiative addressing this process in our local health services.

The first key message in this document is that transition is a process, not simply a transfer of care. Transition occurs over time and is tailored to each individual young person, their family/caregivers, their developmental stage, their chronic condition, and with appropriate cultural considerations. The second point is that it is important to identify and engage adult health professionals early in the transition process so that the young person feels comfortable with differences in service provision when the transfer occurs, and to set clear start and end points for the transition process. The third point is to allow patients and health professionals time to support a mutual task of comprehending the scope of services and manner of how young people access these in the adult world. This will include health services from adult specialists, GPs and allied healthcare professionals in adult health settings, with the aims of managing the chronic condition while at the same time facilitating getting on with the rest of emerging adult life. Managing living with a chronic condition while pursuing tertiary education, vocational or life skills training, open, supported, part time or full-time employment, sport and recreational options, managing more mature relationships, making and reaching goals are examples within this scope. Importantly for some, the re-assessment of any associated disability is paramount in this section of transition. This means a re-evaluation of the logistics of building the right disability supports required by that young person to live a financially secure, vocational, social and community rich life, to have access to healthcare including hospitalisation, aids, living healthily, visiting doctors, of being aware of carer and financial supports, and of the National Disability Insurance Scheme.

The initiators of the *Framework* have purposely consulted widely and wisely. The presented concept of transition of health care helpfully covers stages of increasing independence within the childhood period and then the critical transition through to young adulthood. The sections of the *Framework* highlighting examples of young people with specific chronic conditions are excellent. The *Framework* is sufficiently non-prescriptive to permit its use and refinement to a more detailed transition depending on differing circumstances of individuals and differing circumstances of chronic conditions. This document is a very pragmatic approach, able to be read by young people, their families and their health professionals and is a wonderful contribution to better healthcare of young Tasmanians with chronic conditions.

Wallace

Clinical Associate Professor Robyn A Wallace
Chair, Tasmanian State Committee
Royal Australian College of Physicians

Contents

Acknowledgements

Moving on Up – A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care builds on:

Tasmanian initiatives

- Transition tools and processes – Tasmanian Cystic Fibrosis Service, 2010 – ongoing
- Healthy Tasmania Five Year Strategic Plan 2016–2021 in draft
- Primary Health Tasmania's
    - Tasmanian *HealthPathways*
    - Care Coordination Guidelines 2015
    - Shared Transfer of Care Framework for Action 2015
    - Talking Points – Guidelines for Shared Transfer of Care 2014

Interstate initiatives

- 'Transition Care Network for Young People with Chronic Illnesses/Disabilities Framework' – New South Wales, 2013
- 'Paediatric Chronic Diseases Transition Framework' – Western Australia, 2009

Royal Australian College of Physicians initiatives

- Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services, 2014
- Transition to Adult Health Care Services for Adolescents with Chronic Conditions, 2006

Contributors

2016 Framework

Primary author of the original (2016) Framework was Nicole Saxby, statewide paediatric coordinator and dietitian with the Tasmanian Cystic Fibrosis Service.

Members of the Tasmanian Children's Transition Reference Group assisted in development of the original Framework:

- Gaylene Bassett (paediatric nurse) – North West Regional Hospital
- Associate Professor Sean Beggs (paediatrician) – Royal Hobart Hospital
- Dr Jane Cooper (general practitioner) – Don Medical Clinic
- Angela Diffley (paediatric physiotherapist) – North West Regional Hospital
- Naomi Erends (adult diabetes educator/nurse practitioner) – private practice
- Denise Fletcher (adult occupational therapist) – North West Community
- Karen Ford (research and practice development nurse) – Royal Hobart Hospital
- Cindy Hollings (allied health director) – Launceston General Hospital
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- Cassandra Tichanow (paediatric nurse – Royal Hobart Hospital
- Clinical Associate Professor Robyn Wallace (adult general physician) – Calvary Private Hospital
- Nadia Zalucki (paediatric and adult physiotherapist) – Launceston General Hospital

Dr Michelle Williams, Dr Anagha Jayakar, Dr Susan Diamond, Laura Cini, Diane Webb, Elida Meadows, Jennifer Summers, Lynette Purton and Jane Lucas-Banks also contributed.

2018 update

Members of the original reference group (minus Naomi Erends and Denise Fletcher) were reconvened as the Moving on Up Implementation Advisory Group in August 2017, with the following additional members:

- Dr Paul MacIntyre (adult physician) - Royal Hobart Hospital
- Dr Alasdair MacDonald (adult physician) - Launceston General Hospital
- Dr George Mabeza (consultant physician and clinical lead, medicine - North West Regional Hospital.

The Tasmanian Cystic Fibrosis Service was represented by Nicole Saxby, Rima Aalto and Kirrilee Waterhouse.

The Framework was revised based on advice from this group and KP Health.

The Tasmanian Department of Health have endorsed the use of this Framework to support the transition of Tasmanians from paediatric to adult health services

1. Introduction

Chronic conditions affect the everyday lives of approximately 40 per cent of young Australians (1) – **that's nearly 64,000 Tasmanians!** (2) See figure 1.

A chronic condition of childhood is:

> *A medical condition of more than [6] months duration, and/or; persistent functional limitations; and/or use of healthcare services beyond usual care (beyond resolvable developmental issues – e.g. preschool speech therapy)* (3 p.1)

This definition has been amended from the 2007 Cincinnati Children's Hospital Chronic Condition Self-Management Guideline (3) to suit the Australian healthcare context. Chronic conditions can range from relatively minor conditions such as allergic rhinitis and asthma which affect up to 1 in 10 children, (1) to more complex conditions such as type 1 diabetes mellitus and cystic fibrosis which affect less than 1 in a 1000 children. (4, 5) **Of particular concern is that a large number of young people who grow up with chronic conditions of childhood fail to successfully transition to adult services.** (6, 7)

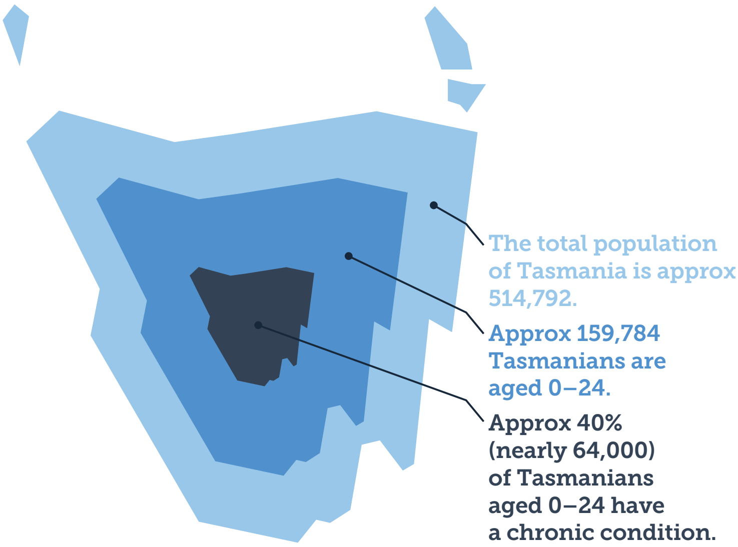
It is important for clinicians to recognise that transition is a process, not a single administrative event. (8) The transition process needs to be guided, developmentally appropriate, educational and therapeutic. (8, 9) A well accepted definition of **transition** is:

> *the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from family/child-centred to adult-oriented healthcare systems* (10 p.570)

During childhood and adolescence, there is a gradual shift from parents and other adults supervising all aspects of the child's medical care, to the child and young person taking on increasing responsibilities in self-management. While younger children cannot be expected to assume full responsibility for management of their chronic condition(s), over time they can be encouraged to become more actively involved, together with their family/caregivers and clinicians. There is a growing body of evidence that well planned transition processes, emphasising early self-management support (e.g. educational programs, skills training) and care coordination (e.g. joint clinics run by paediatric and adult clinicians, enhanced follow-up), leads to better health outcomes and quality of life, and a reduction in health service use. (11, 12)

Unlike other Australian states, Tasmania has not had a Framework to guide the transition from paediatric to adult healthcare services in place. The development of this *Framework* addresses this gap and provides healthcare practitioners with a recommended staged process to guide transition, from birth to young adulthood.

Figure 1 estimated percentage of Tasmanian young people (0 – 24 years) living with a chronic condition(1, 2)



Aim

The aim of *Moving on Up – A practical framework to support young Tasmanians with chronic conditions transition to adult care* (referred to as the *Framework*) is to support successful transition of young people to adult health services. This will optimise young people's health and their ability to adapt to adult life successfully, including developing self-management skills.

Objectives

- to build the self-management skills and abilities of the young person and their family
- to improve the coordination of care of the young person during and after transition
- to strengthen communication and collaboration between service providers and consumers
- to support clinicians to understand and implement the *Framework*.

Practice Point: condition versus disease

The term 'chronic condition' is better suited to the needs of young people than the term 'chronic disease'. Despite these terms often being used interchangeably by clinicians, there are differences between them. 'Condition' refers to a state of health, whether well or ill. (13) In contrast, 'disease' denotes a condition that is characterised by functional impairment, structural change and the presence of specific symptoms, which adversely affect the individual. (13) The *Framework* uses the term 'condition' in place of 'disease', in light of this distinction.

1.1 Self-management and transition

Developing self-management skills helps to prepare young people for transition by enabling them to understand and access the services that they will need in their adult lives. (12)

In the context of this *Framework* self-management can mean the young person solely taking on the role, but it may also mean that the ongoing assistance of family members or caregivers is required due to the nature or severity of their condition (or disability) or because it is their choice.

A young person's ability to self-manage is multi-factorial. Clinicians need to be aware of factors that are modifiable and those that are not (i.e. are non-modifiable). Modifiable factors are those that planned interventions can impact on. Non-modifiable factors are those that are not typically targeted in intervention. For more information, see table 1 below:

Table 1 **Factors affecting self-management ability in young people** (12)

	Modifiable	Non-modifiable
young person	• disease and treatment knowledge • child internalising/externalising symptoms • coping style • health beliefs and perceptions (e.g. self-efficacy, perceived stigma)	• age • gender • developmental level • cognitive functioning (e.g. IQ) • sociocultural factors (e.g. race/ethnicity, religion)
family/caregivers	• disease and treatment knowledge • family internalising/externalising symptoms • family coping style • health beliefs and perceptions • family functioning • relationship quality • parental monitoring and supervision • parental involvement	• parental marital status • family structure • cognitive functioning (e.g. IQ) • insurance coverage • income • education • sociocultural factors (e.g. race/ethnicity, religion)
community	• peer support • social stigma • school-based accommodations related to health • availability of social networking	• neighbourhood • availability of resources to support positive healthcare behaviours
healthcare system	• patient-provider communication • frequency of clinic visits • medical training models	• availability of healthcare resources (e.g. access, including location and frequency and health insurance)

Table above modified from Modi 2012 (12): Table 1, Examples of the influences, processes, and behaviours of paediatric self-management, p. e477

Practice point:
self-management support tool

The acronym **KIC MR ILS**, developed by the Flinders Human Behaviour and Health Research Unit, is a useful prompt for clinicians. This acronym can be used with young people to help them understand and remember the core principles of managing their condition.

- **K**now your condition
- be actively **I**nvolved with the general practitioner and other clinicians
- follow the **C**are plan that is agreed upon
- **M**onitor symptoms and **R**espond to them
- manage the physical, emotional and social **I**mpact of the condition(s)
- live a healthy **L**ifestyle
- readily access **S**upport services

For more information go to
www.flindersprogram.com.au

1.2 A developmental perspective to transition

A developmental perspective of transition has been chosen as the basis for this *Framework* because it takes into consideration how young people think and behave from birth to adulthood. A young person's level of development will influence:

- how they understand and react to their chronic condition
- what healthcare tasks they can begin to undertake on their own and those they require ongoing assistance with managing, and
- the way they learn and therefore how they can be educated to undertake their own healthcare. (15)

Practice point:
assessing developmental status and progress

Assessment of developmental status and progress should be completed regularly as part of the transition process. (16) An interdisciplinary team can help to ensure a comprehensive assessment (e.g. a young person's cognitive abilities, problem solving skills, motor abilities, strengths and weaknesses that may affect treatment implementation). (7, 16, 17)

1.3 The rights of the child

All policies and practices in healthcare should reflect the rights of the child. The Children's Hospitals Australasia (18) recognises young people's healthcare rights. The rights of young people are described as:

- consideration of what's in our best interests
- to express our views respectfully, be heard and have something done about it
- to use and receive the best available healthcare
- to be treated with respect in regards to our values, beliefs and culture. We have a right to be ourselves
- to be with and guided by our family, unless it is against our best interests
- to be involved in making decisions that affect us
- to be kept safe from all harm
- to have our privacy protected and respected
- to education, rest, play, creative activities and recreation
- to planned coordinated healthcare
- to be fully informed, ask questions and be given answers about all matters concerning us.

These rights align with the United Nations Key Principles on the Rights of the Child. (19)

2. Scope

2.1 Purpose

The *Framework* is designed to:

- raise awareness among Tasmanian clinicians of the need to support young people to develop the skills, knowledge, and behaviours they and/or their families/caregivers need to manage their own condition as they transition to adult care
- embed a transition focus into everyday practice
- increase understanding of the key elements of transition
- improve transition planning and preparation
- tailor transition processes so that they are developmentally and age appropriate, and
- improve communication, coordination and collaboration between young people, families and their service providers, as well as between the different service providers.

2.2 Target users

The *Framework* has been created for Tasmanians involved in delivering health services to children and young people accessing primary services (e.g. general practitioners, community and youth health nurses, allied health professionals), secondary services (e.g. clinical specialists such as cardiologists), and tertiary services (e.g. hospital coordinated interdisciplinary healthcare team). Clinicians is the term used in this document to refer to the diverse healthcare disciplines and health professionals who are directly involved in care of young people and young adults.

2.3 Target population

The target population of the *Framework* is young people with chronic conditions who access services within the Tasmanian primary, secondary and tertiary healthcare systems. This *Framework* is applicable across life stages from infancy through to late adolescence and early adulthood (birth up to 24* years of age (20)).

The impacts that specific health-related issues, social and economic considerations, cultural influences, and geographical conditions can have for transition are considered in section five: 'Considerations for specific groups' (page 28). Examples of health conditions affecting young people include:

- asthma
- acquired childhood chronic injuries
- cancer
- cystic fibrosis
- diabetes mellitus (type 1 and type 2)
- developmental disabilities (physical, sensory and intellectual)
- eating disorders
- epilepsy
- gastrointestinal conditions
- heart conditions
- juvenile idiopathic arthritis
- mental health conditions
- obesity

* The *Framework* may also be applicable to individuals older than the target age group depending on individual circumstances and geographical isolation.

2.4 How does this *Framework* link with other initiatives?

The *Framework* aligns with the Australian health priority areas and the following documents:

- One State, One Health System, Better Outcomes Delivering Safe and Sustainable Clinical Services. Tasmanian Government White Paper June 2015
- National Statement on Health Literacy, Australian Commission on Safety and Quality in Health Care, 2015
- Primary Health Tasmania's
    - Tasmanian *HealthPathways*
    - Care Coordination Guidelines 2015
    - Shared Transfer of Care – Framework for Action 2015
    - Talking Points – Guidelines for Shared Transfer of Care 2014
- Australian Privacy Principles, Australian Government Office of the Australian Information Commissioner, 2014
- A Framework to Support Self-Management, Department of Health and Human Services, Tasmania, 2012
- The National Safety and Quality Health Services Standards, Second Edition, 2017
    - Standard 1 – Clinical Governance
    - Standard 2 – Partnering with Consumers
    - Standard 6 – Clinical Handover

  www.safetyandquality.gov.au/our-work/assessment-to-the-nsqhs-standards/nsqhs-standards-second-edition
- National Strategic Framework for Chronic Conditions www.health.gov.au/internet/main/publishing.nsf/content/nsfcc

2.5 Methodology

Primary Health Tasmania facilitated a care coordination program from 2013-16 for clients with complex chronic diseases, funded under the Tasmanian Health Assistance Package. During this time it was identified that Tasmanian clinicians needed more guidance to support young people to successfully transition to adult health care services. Anecdotal evidence for this need was collected through consultation with service providers and consumers across Tasmania.

Collaboration between Primary Health Tasmania and the Tasmanian Health Service from 2015, especially the cystic fibrosis program, led to the development of Moving on UP – *A Practical Framework to Support Young Tasmanians with Chronic Conditions Transition to Adult Care*.

The *Framework* builds on a long-standing quality improvement project (since 2010), aiming to improve the transition process for young people with cystic fibrosis.

Two key authors, plus a project officer coordinated the development of the *Framework*. A reference group of clinicians working in paediatrics, primary health care, general practice and adult services was convened to assist in the development of the *Framework*.

Regular meetings were held with the reference group to discuss priority topics to be included in the Framework. Draft versions of the Framework were completed and sent to the reference group members for discussion, revision and comment. Preliminary feedback was requested from the Tasmanian Health Service Women and Children's Clinical Advisory Group.

The *Framework* was released for public consultation, as recommended by the National Health and Medical Research Council,(21) from 26 October 2015 to 27 November 2015. Twelve submissions were received from health departments, non-government organisations and individual clinicians; comments were integrated into the final document.

In 2017, an external review of the *Framework* was undertaken to inform the development of resources and tools to support its implementation.

The review confirmed the *Framework* is consistent with best practice in supporting young people with a chronic condition transitioning from paediatric to adult services as reported in the international peer-reviewed literature and reflected in national and international guidelines for supporting transition.

It is important to recognise that this is an evolving area of practice, where national and international research is continuing to contribute to a policy environment that is both iterative and emerging. It is important that over time the *Framework* be reviewed to ensure continued best practice in supporting young people with a chronic condition transitioning from pediatric to adult services.

The Reference Group was reconvened as an Advisory Group to provide expert advice to support the implementation phase.

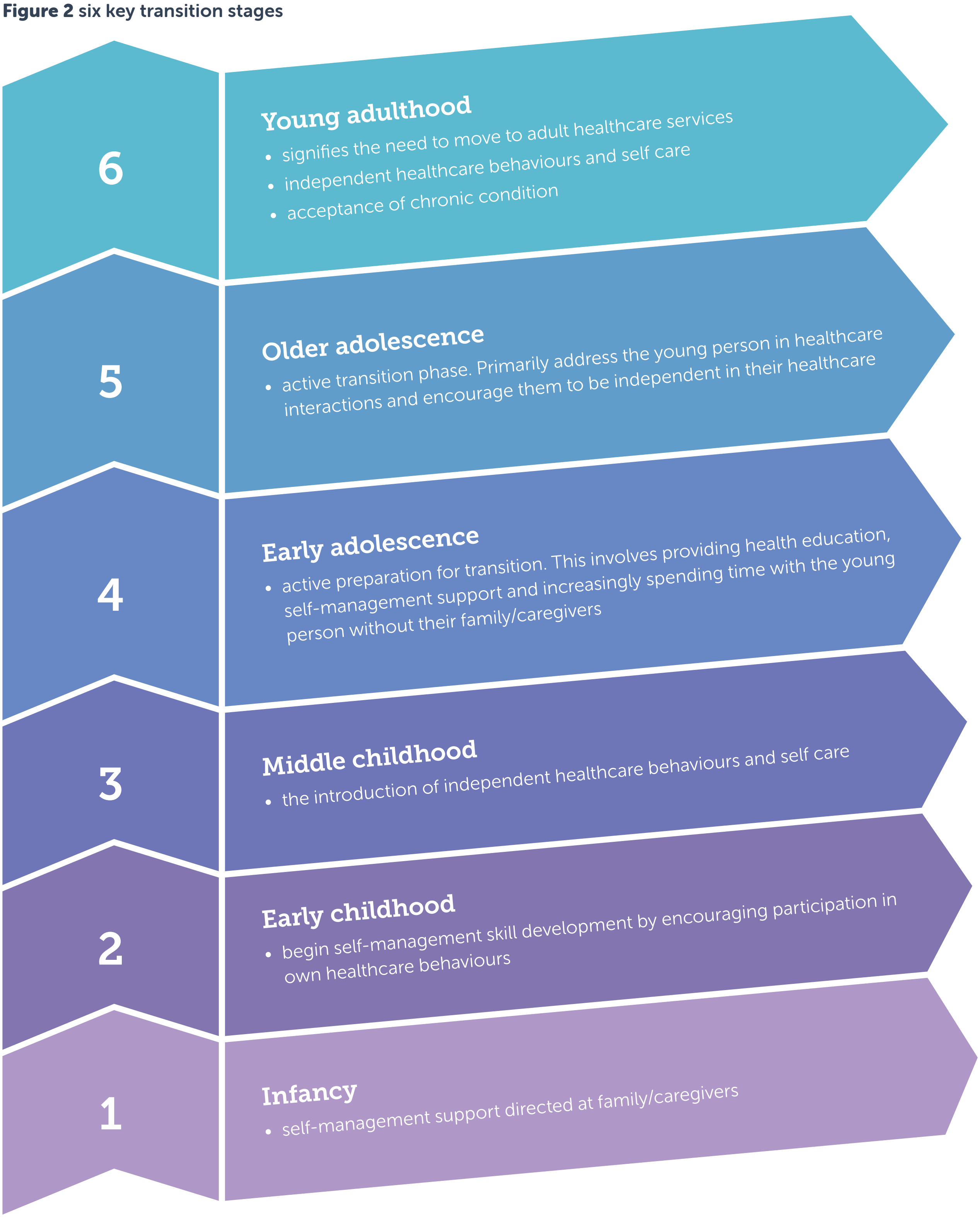
3. Moving on UP

‘Moving on Up’ presents a staged approach to transition that recognises health services need to take a life-course approach to working with young people with chronic conditions and their families. Preparation for transition through enabling self-management should begin at diagnosis, whatever age this may be.

Starting self-management support early enables young people to develop the skills, behaviour and confidence they need to look after their condition, over an extended period of time.

The *Framework* proposes that there are six key transition stages.

Figure 2 six key transition stages



6 **Young adulthood**
- signifies the need to move to adult healthcare services
- independent healthcare behaviours and self care
- acceptance of chronic condition

5 **Older adolescence**
- active transition phase. Primarily address the young person in healthcare interactions and encourage them to be independent in their healthcare

4 **Early adolescence**
- active preparation for transition. This involves providing health education, self-management support and increasingly spending time with the young person without their family/caregivers

3 **Middle childhood**
- the introduction of independent healthcare behaviours and self care

2 **Early childhood**
- begin self-management skill development by encouraging participation in own healthcare behaviours

1 **Infancy**
- self-management support directed at family/caregivers

There are several limitations to using a stage-based approach to transition and self-management skill development, including:

- young people achieve self-management milestones at varying rates, with intervals of rapid progress, versus periods of slower development (often observed during adolescence)
- age estimates provided can only be used as an approximation of when clinicians might begin to see self-management skill development. Young people can, and do, achieve milestones before and after the proposed anticipated timeframes. This is not necessarily indicative of advanced or impaired transition progress
- transition does not necessarily occur smoothly or in one direction. The trajectory of life experience or illness can affect self-management, with a young person sometimes regressing.

Consideration also needs to be given to special need population groups, such as young people with developmental disabilities, See section 5: ‘Considerations for specific groups’ (page 28).

1

Transition Stage 1
Infancy (approximately 0–3 years)

Development

Stage characterised by:

- forming of trusting relationships between the infant and their family/caregivers and any others involved in their care
- increasing body awareness
- object permanency
- stranger anxiety
- beginning to learn meaning of words and speaking
- unable to communicate needs and indicate health needs

Chronic condition considerations

Family/caregiver

- emotional adjustment to infant's diagnosis
- mental health concerns are more common in family units affected by chronic conditions

Infant

- fussy eating behaviours more common in infants with chronic conditions
- difficulty swallowing pills/taking medication
- increased potential for disturbed sleep patterns

Support approaches

Family/ caregiver

- direct self-management support to family/caregivers

Infant

- support learning body awareness and parts as well as verbal labels for symptoms
- support knowing routines and what is expected
- allow some choices (e.g. pick a story or select an activity to complete after treatments)

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the family/caregiver to:

- **(K)** know and understand the condition
- **(I)** work in partnership with clinicians
- **(I)** have adjusted to the diagnosis
- **(C)** administer medical and lifestyle treatments as required
- **(L)** promote active play
- **(L)** promote a diet suitable to the infant's condition

At the end of this stage we are aiming for the infant to:

- **(C)** be accepting of daily treatments
- **(C)** help family/caregiver to set up treatment areas

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

2

Transition Stage 2
Pre-school years (approximately 3–6 years)

Development

Stage characterised by:

- development of significant cognitive, social, mechanical and emotional skills
- consolidation of their self-esteem in respect to their peer group
- child beginning to develop confidence in their own abilities

Chronic condition considerations

- fussy eating habits and disturbed sleeping may continue into this stage
- may have trouble understanding the implications of their chronic condition
- antisocial behaviours are more common in pre-schoolers with chronic conditions (e.g. inappropriate, disruptive or disobedient behaviours)

Self-management Support approaches

Family/ caregiver

- continue to primarily address family/caregiver in relation to self-management support

Pre-schoolers

- encourage normal childhood interactions and experiences
- promote child participation in treatments
- give child simple explanations (e.g. 'this medicine will')
- use games to help with decision making
- may need reassurance that they are not being punished for being unwell

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the pre-schooler to:

- **(K)** know and understand that medications/treatments will make them feel better
- **(K)** be able to identify many external body parts
- **(I)** know the names of their clinicians
- **(C)** use a spacer or other simple device with assistance
- **(C)** swallow medications in tablet/capsule form
- **(MR)** describe how they feel
- **(MR)** recognise some early warning signals (e.g. "wobbly" if hypoglycaemic)

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

3

Transition Stage 3
Primary school years (approximately 7–11 years)

Development

Stage characterised by:

- continuing development of cognitive, social, mechanical and emotional skills
- continuing consolidation of their self-esteem in respect to their peers
- increased ability to relate to others
- child beginning to initiate their own activities

Chronic condition considerations

- growing awareness of being different to their peers
- often blame themselves for their chronic condition
- may lack energy to play at the same level as their peers

Support approaches

Family/caregivers

- encourage family/caregivers to give the child increased responsibility in communicating with their clinicians
- provide family/caregivers with a copy of the care plan (treatment regimen)

Child

- encourage normal childhood interactions and experiences
- begin to address child more directly in discussion of care
- able to report and recognise symptoms
- demonstrate exercises
- take medicine when reminded (eventually without reminders)
- encourage responsibility and chores
- use reward systems (e.g. star charts)
- create choice opportunities for the child
- coach the child to communicate with family/caregivers, teachers, clinicians about concerns
- use simple pictures and stories to explain health concepts and stimulate problem solving
- encourage interaction with technology and its platform as a communication tool and source of support information

Schools/community groups

- supply with information to assist with increasing levels of self-management

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the child to:

- **(K)** be able to identify internal body structures and the function of a specific body part (e.g. lungs for breathing)
- **(K)** have a basic knowledge of their condition and treatments (e.g. why they need treatment and what it does)
- **(K)** name their prescribed treatments including order and timing
- **(I)** engage with clinicians by answering simple questions
- **(C)** know how long to perform each treatment
- **(MR)** recognise, report and respond to significant symptoms (e.g. asthma attack, hypoglycaemia, infection)
- **(I)** talk to others about their condition including their peers and teachers
- **(L)** follow a healthy diet suitable to their condition
- **(L)** be physically active at school and at home, participating in sport activities if able to
- **(S)** consider attendance at chronic condition support camps

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

4

Transition Stage 4
Early adolescence (approximately 12–14 years)

Development

Stage characterised by:

- abstract thinking (right versus wrong)
- egocentricity and mood swings
- physical, hormonal and pubertal changes
- rapid growth and significant changes in bodily appearance (body image and concern for normal growth are common)
- shift from parental influence to peer influence
- amplified intensity of emotion, which may lead to increased family/caregiver conflict
- developing a sense of their own responsibility and identity
- increasing reasoning and problem-solving skills
- increased independence and thrill seeking

Chronic condition considerations

- potential instability of condition/s
- changes in treatment requirements
- high potential for refusal to comply with treatments
- adoption of sick role as personal identifier or denial of condition
- reduced independence at a time when independence is normally developing
- risk taking behaviour more common in adolescents with chronic conditions
- social isolation

Support approaches

Family/caregiver

- encourage family/caregivers to be good role models, especially around forming and maintaining healthy relationships and for positive ways of dealing with difficult emotions

Adolescent

- increasingly address the young person directly in regards to their health and treatments rather than their parents
- encourage the young person to attend part of the appointment by themselves
- have open discussions about the division of responsibility of healthcare tasks with both the young person and their family/carers in the move towards independence
- long term goal would be for the young person to undertake own treatments independently (e.g. prepare and take medications and follow physical and dietary recommendations)
- anticipate possible side effects of treatments that may be bothersome
- encourage the young person to demonstrate good preparation and judgement when looking after themselves when away from home
- with guidance from their family/caregivers, encourage the young person to keep written records of medications, care plan and their symptoms as required
- a 'health contract' may be beneficial; role play occasionally helpful
- use models/diagrams when clarifying information
- encourage interaction with social media as a communication tool and source of support information

Schools/community groups

- supply external groups with information to assist with increasing levels of self-management

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the adolescent to:

- **(K)** learn the mechanisms of complex medications and/or treatments
- **(I)** be comfortable seeing their clinicians alone for short periods of time
- **(C)** be aware of their exacerbation and/or emergency plan
- **(C)** learn to dose medications appropriate (e.g. insulin to carbohydrates ratios or pancreatic enzymes to fat)
- **(I)** enjoy interaction with friends and family
- **(L)** explain how the body uses food as fuel and how physical activity uses energy
- **(L)** keep up a healthy diet and exercise regime

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

Practice point: sexual health

Clinicians need to target sexual health as part of the transition process as sexual health is an area of utmost importance to young people, (16) therefore throughout the adolescent stages, paediatric and adult teams need to consider the young person's pubertal status, sexual attitudes and behaviours. (16, 27)

5

Transition Stage 5

Late adolescence (approximately 15–18 years)

Development

Stage characterised by:

- forming of identity (who am I and where do I belong)
- egocentrism continues but, ability to make moral decision increases
- adolescent may want to spend less time with family and more time with friends and peers
- sexual experimentation and identification
- altered perception of risks and thrills
- changes to sleep cycle
- sensitivity to alcohol and other drugs
- gender differences in maturity levels
- changing priorities and increases in stress due to study, work and increased social life

Chronic condition considerations

- potential instability of condition
- changes in treatment requirements
- may refuse to comply with treatments and/or accept condition
- difficulty in imagining the future; can perceive self as being "bullet proof"
- increased risk-taking behaviours – smoking, alcohol and drug use often in excess of normal population rates
- for some young people, leaving trusted paediatric services can equal a sense of loss, abandonment, uncertainty and/or anxiety; others may reject their clinicians as part of separation from their family/caregiver

Self-management Support approaches

Family/caregiver

- assist the family/caregiver in providing safe opportunities for their adolescent to practice independence
- highlight to the family/caregivers healthcare activities that the adolescent is doing well

Adolescent

- primarily address the young person
- continue to have open discussions about healthcare responsibility
- ask the adolescent to identify potential obstacles to treatment/s
- encourage independence in all aspects of care
- model healthy behaviours
- encourage interaction with social media as a communication tool and source of support information

Schools/community groups

- supply external groups with information to assist with increasing levels of self-management

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the young person to:

- **(I)** be able to describe changes in their health to their family/caregiver and clinicians
- **(I)** share in decisions relating to their treatments, medications, tests and clinical appointments
- **(I)** be willing to meet members of their future adult healthcare team
- **(C)** be independent with most treatments
- **(MR)** keep accurate health records
- **(I)** be aware of their mental health (e.g. coping, anxious, depressed)
- **(L)** make healthy lifestyle choices around diet, exercise, alcohol, smoking, drug taking, sexuality and relationships
- **(S)** consider attendance at chronic condition support camps and/or support groups

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

6

Transition Stage 6
Young adults (approximately 18–24 years)

Development

Stage characterised by:

- greater complexity of thinking
- developing critical thinking skills
- continued integration or cognitive and emotional skills
- transition from high school to making career choices (higher education or employment)
- decisions move more towards impact on others and future thinking

Chronic condition considerations

- potential instability of condition/s
- changes in treatment requirements
- leaving trusted paediatric services can equal a sense of loss, abandonment, uncertainty, anxiety. Young adult will need to rebuild trust with adult clinicians

Support approaches

Family/caregiver

- let the young adult have independence
- with permission of young adult, encourage family/caregiver to act as a safety net

Young adult

- encourage independence in all aspects of care
- foster growth towards next step in life (goal setting)
- provide instruction in critical thinking
- promote interdisciplinary and interactive approaches
- encourage diversity of peers

Specific populations (e.g. developmental disability, homeless) may require access to modified accommodation

Self-management skills KIC MR ILS*

At the end of this stage we are aiming for the young adult to:

- ideally be able to perform all self-management tasks independently
- make healthy choices

KIC MR ILS(14) **K**nowledge – **I**nvolvement – **C**are plan – **M**onitor and **R**espond – social **I**mpact – healthy **L**ifestyle – **S**upport services

Stages synthesised from the following literature: (1, 3, 15, 28–37)

4. The core components

There are five core components of effective transition:

1. Young person- and family/caregiver-centred care
2. Shared responsibility
3. Coordinated care
4. Readiness for transfer
5. Skilled workforce

Core component 1.

Young person- and family/caregiver-centred care

Young person- and family/caregiver-centred care means that the young person and their family/caregivers are placed at the centre of their health and wellbeing, thereby creating a respectful and collaborative partnership between the clinicians, the young person and their family/caregivers.

The end goal is self-management support, where the young person and their family/caregiver self-manage their chronic condition/s to the best of their ability. When young person- and family/caregiver-centred care is the focus they are placed at the centre of all healthcare efforts, and are empowered to manage their own care as best they can. This doesn't mean that they will not need anyone else's help, but that they will have the confidence to understand what they need to do, when they need to do it, how they can accomplish it, and where they can find help if and when they need it. This includes providing condition-specific education, and specific information on the transition process for people with their condition.

The American Academy of Paediatrics defines young person- and family/caregiver-centred care as:

> *an innovative approach to the planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among patients (young people), families and providers, that recognize the importance of the family in the patient's life* (38)

This definition acknowledges that as a young person grows up they become more active participants and decision-makers in their own healthcare.

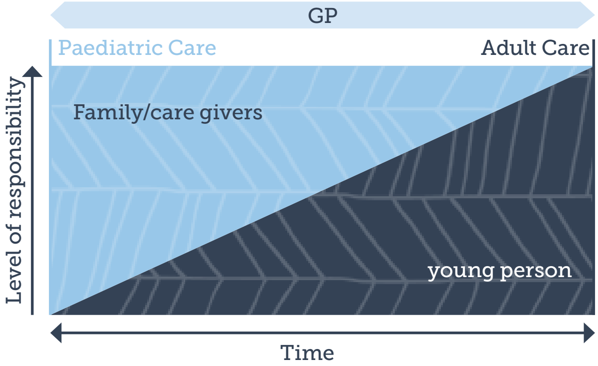
Throughout the transition process it is important that:

- young people and their families/caregivers are treated with dignity and respect
- young people and their families/caregivers are active partners in decision-making processes and share in the provision of care to the extent possible
- young people with complex needs and their families/caregivers are prioritised for transition support
- health providers and family/caregivers have realistic expectations of young people's ability to self-manage, especially where this may be limited (for example, for many young people with developmental disability), and this is reflected in planning for transition.

Core component 2.
Shared responsibility

Shared responsibility involves young people, family/caregivers and clinicians working together as a transition team and acting as partners in the management of chronic conditions, as shown in figure 2 below. (12, 16, 39, 40)

Figure 2 diagrammatic representation of the shared responsibility of transition



Shared responsibility can be achieved by:

- the **young person** owning the transition process
- their **family/caregivers** acknowledging the young person's growing autonomy at all stages of the transition process
- clinicians being accepting of the young person's growing autonomy and readiness for transition and supporting them through this process (23, 41)
- **paediatric clinicians**
  - working collaboratively with the young person's General Practitioner (GP)
  - promoting positive self-management behaviours at every interaction (42)
  - facilitating discussions between the young person and their family/caregiver about how the division of responsibility for health tasks is shared (42)
  - being aware of options that are available in the community to further support the young person (peer support and social networking)
  - identifying appropriate adult care clinicians/teams for the young person, nurturing a relationship with adult physicians and medical departments to initiate transitions, and avoiding one-visit transfers of care of the young person
  - promoting interactions between the young person and adult healthcare team as they prepare for transition and the move towards transfer to adult services (this will help young people build trust with adult healthcare providers and will reduce anxieties associated with transfer) (43)
  - ensuring transparent and timely communication between the paediatric and adult care teams, as well as the young person and their family
  - be prepared to "let go" of the young person
- **adult clinicians** being prepared to accept the person into adult care, recognising the needs of young people will be different to other groups (45)
- **a general practitioner** being involved throughout a young person's life and having an awareness of the full transition process.

Practice point: involving general practice

All young people are encouraged to have a general practitioner throughout their life who can act as a central point for their coordinated care.

The general practitioner and general practice team will:

- be the primary point of contact from birth for day-to-day health issues i.e. normal growth and development issues, normal illnesses of childhood and immunisation
- provide regular follow-up of all young people with chronic conditions
- work collaboratively with paediatric clinicians
- be prepared to take on increased responsibility after transfer to adult services to support the young person to self-manage their chronic condition
- the general practitioner may remain the only continuous clinician throughout the transition process.

Chronic Disease Management Medicare items *are available for general practitioners to help them manage the healthcare of people with chronic or terminal medical conditions, including those requiring multidisciplinary, team-based care from a general practitioner and at least two other health or care providers. (taken from the MBS online www.mbsonline.gov.au)* (46)

Fact sheet available at – www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-factsheet-chronicdisease.htm

Core component 3.
Coordinated care

Care coordination involves deliberately organising a young person's healthcare activities and sharing information among the clinicians involved. This planned and managed approach ensures that the best health outcomes are achieved for the young person and their family/caregivers and that health services are effectively and efficiently used.

The main goal of care coordination is to meet patients' needs and preferences, provide safe, appropriate and effective high-quality, high-value healthcare and:

- to ensure clients have capacity to be in control of their healthcare
- to improve access to necessary services to help support improved health outcomes – particularly for the young person with chronic and complex conditions
- to reduce inappropriate and avoidable service use across the healthcare sector – particularly in relation to potentially avoidable hospitalisations, emergency department presentations, and emergency admissions involving people with complex chronic care needs
- increase communication between healthcare providers.

Coordinated care is a comprehensive approach to achieving continuity of care for people with chronic conditions from childhood into adulthood. With the right services and clinicians engaged, young people will be able to access healthcare and supports across a range of clinicians who work collaboratively.

Clinicians can ensure a coordinated care approach by:

- identifying a key worker to support throughout the transition process. This may be a general practitioner, but could also be a nurse navigator, peer worker, or relevant allied health professional.
- ensuring that the young person and their family/caregiver are informed and involved at each life stage
- sharing information clearly and openly with the young person and their family/caregiver and ensuring that the general practitioner is kept up to date
- keeping high-quality clinical documentation that is shared across services (timely, appropriate, routine and non–routine)
- the use of secure information technology to facilitate transfer of information
- having effective channels of communication between clinicians, services, the young person and their family/caregivers, e.g.
    - family meetings
    - a written healthcare transition plan (16)
    - an accurate compilation of the patient's complex medical information which should be developed so that it is accessible and available to the young person, their family/caregiver, and adult health care providers. (16)

Core component 4.
Readiness for transfer

Services should maintain a registry of young people to identify who is ready to start the transition process as well as to track progress and outcomes. Active planning for transition should start in early adolescence.

The readiness for transfer for individual young people is varied and reliant on multiple factors including age, capacity, and available services. When considering the timing of transfer it is important to ensure that it does not coincide with other major life changes such as exams, commencing employment, or starting university. (16) It is also important to consider the medical and emotional stability of the young person.

From early adolescence, clinicians should be regularly assessing the young person's self-management skills and readiness for transfer. There are a variety of generic and condition-specific 'readiness to transfer' tools available for use.(47)

Practice point:
no local adult specialist services available

Many local areas in Tasmania lack condition-specific adult services or clinics to which a young person can be transferred. Local paediatric teams, their adult physician counterparts and general practitioners must work together during this time. Adult physicians must be prepared to accept and go through the process of transition of new young adult patients, and paediatricians must be prepared to nurture a relationship with adult physicians and medical departments and to initiate transitions, and avoid one-visit transfers of care of the young person.

Because of Tasmania's relatively small population, some statewide services are centrally based. Combining use of government subsidy transport systems for face-to-face appointments with telehealth consultations offers potential to optimise access to health care for patients living in rural and regional areas. Sharing of knowledge of skills and local supports may be optimised additionally via interdisciplinary teleconferences and consultations.

Core component 5.

Skilled workforce

Effective transition requires a highly skilled and supported workforce able to demonstrate clinical leadership and provide interdisciplinary care. (16, 48) Core capabilities of a skilled workforce are presented in Table 2.

Table 2 Core capabilities of a skilled workforce (48)

General patient-centred capabilities	Behaviour change capabilities	Organisational/systems capabilities
• communication skills • health promotion approaches • assessment of health risk factors • assessment of self-management capacity (understanding strengths and barriers) • collaborative care planning • cultural awareness • psychosocial assessment and support skills • working with the family/caregiver unit	• models of health behaviour • motivational interviewing • collaborative problem solving • goal setting and goal achievement • structured problem solving and action planning	• ensure information, assessment and communication management systems enable the sharing of all patient information between all clinicians involved in care • working in interdisciplinary teams/ interprofessional learning and practice • organisational change techniques • evidence-based knowledge • conducting practice-based research/quality improvement Framework • awareness of community resources • allow technologies for communicating with young people (e.g. mobile phones, internet, email and social media).

Table above modified from Lawn S and Battersby M.2009 (48): Table 2, Capabilities for supporting prevention and chronic condition self-management: A resource for educators of primary healthcare professionals. Flinders University, Adelaide: Australian Government Department of Health and Ageing, p. 12.

Practice point: communicating with young people

When talking with young people it is important to: (47)

- prepare the environment – ensure you have the right space, set up and time
- introduce yourself
- sit at their level, use eye contact, be aware of body language
- use plain language (that is age appropriate)
- provide information in the right way i.e. written, pictures, YouTube
- ask the young person what they already know
- check you have explained things in a way that is understood
- ask open-ended questions
- ask the young person what questions they have

Also, remember that young people frequently use technology for communicating (e.g. mobile phones, internet, email and social media). (49)

5. Considerations for specific groups

'Moving on Up' is appropriate for all young people living with chronic conditions, including those with developmental disability, different cultural beliefs, language barriers and socioeconomic disadvantage. For these groups, clinicians still need to be aware that:

- transition is a process
- adult clinicians must be identified and engaged early
- it will take time to comprehend the scope and availability of adult services that a young person will require on transfer
- the general practitioner is often the only consistent clinician through the transition process from paediatric to adult care.

Additional considerations include:

- the possibility of substitute decision-making and guardianship laws and
- that some young people will not be able to give informed consent before transfer.

The recommendations in this section will help ensure the provision of health care to these vulnerable groups is equitable, efficient and effective.

5.1 Mental health

Transition for young people with mental health issues can be difficult. (50) However, unlike other chronic conditions, there are many mental health conditions faced by young people that are not well catered for in adult services. (51) These include:

- autism spectrum disorders
- attention deficit hyperactivity disorder (ADHD)
- emergent personality disorders
- obsessive compulsive disorders
- eating disorders
- stressful mental health problems that may not clearly satisfy criteria for a particular disorder.

Young people with such diagnoses may have been receiving care from child and adolescent mental health services, however they may fail to meet stricter eligibility criteria for adult mental health services. (51) It is also not appropriate for all young people to transition from child to adult mental health services. (51)

Transition team members are encouraged to:

- focus on prevention and intervene early to address mental health needs in a young person's developmental trajectory
- involve a paediatric psychologist as either part of the transition team or as a consultant
- increase a young person's access to supports by considering enhanced collaboration across sectors (e.g. education, justice, welfare, youth centres, church groups)
- consider referral to Headspace or other youth mental health service (e.g. Anglicare). (16, 52–54)

5.2 Developmental disability

Developmental disability refers to a permanent cognitive and/or physical impairment that usually occurs in the early years of life but can occur any time before the age of 18 years. It results in significantly reduced capacity in three or more major life activities. (55) Activities compromised can include communication; learning; mobility; living independently; decision making; self-care; self-management and ability to seek; and management and participation in their own health. (55)

There are up to 15,000 individuals in Tasmania with developmental disabilities. (56) Although there are well developed and highly successful developmental paediatric services (paediatrician led) there are few specialised and dedicated services in the adult-health sector. (57) Many young people with numerous medical problems may be referred over to their general practitioner after turning 18 but additional referral for possible long term care to a physician specialising in Internal Medicine should be considered. (57) Physicians specialising in internal medicine, though not necessarily specialised in disability, are used to managing the healthcare of people with multiple and complex bio psychosocial histories. (57)

Transition team members need to consider:

That young people with developmental disabilities can have significant issues when compared to their peers in the general population. These can include:

- reduced cognitive and motor functioning
- sensory impairments (vision and hearing)
- pubertal delays and sexual health concerns
- social, sexual and financial vulnerabilities
- multiple physical health comorbidities
- lower healthy living habits
- antisocial behaviours and other difficult behaviours
- parental concerns over achieving the right balance of protection versus independence
- loss of many paediatric school related community programs or supports
- difficulty with peers and self-acceptance
- accessing Centrelink schemes and learning about relevant entitlements such as disability allowances and benefits, healthcare subsidy systems, leaving home options, respite, group homes, accessing National Disability Insurance Scheme, including access to equipment and appliances, seeking disability service providers for residential, day and supported employment options, and refining the roles of disability support services in all the various health settings and managing the health handover from families
- a requirement to fit into generic services instead of specialised paediatric services and facing adult health services which may not be disability aware
- the value of advocacy from the transition team to facilitate the development of resaonble adjustments to the generic adult health systems to minimise barriers in the adult health settings
- feeling intimidated and not confident to be assertive
- optimal health and healthcare access contributes to maximal social participation and opportunities
- an ongoing but variable dependence on disability support from parents, and now additionally the disability service provider sector, to access and participate in adult health services and healthy living(38, 55, 57–60)

Transition team members need to consider:

- develop a professional relationship over time with adult general physicians to oversee the range of medical problems of transitioning young people with developmental disability
- set a start and stop time for transition; complete the transition process with this group over a period of time i.e. 6 months, and prior to the completion of the transition make it clear that the young person is still considered a paediatric patient for acute ilnesses requiring hospitalisation. This allows the clinicians to learn about the young person's personality and behaviour, cognitive and motor skills, home situation, daytime activities, as well as the health issues. This facilitates development of disability supports plans for the young person to access and participate in all aspects of health care and health processes
- be prepared to make reasonable adjustments in adult health services such as longer and more frequent appointments, at least in the early stages
- spend time discussing how the management of inpatient hospital care could occur and the role of family or carers disability supports in adult hospital wards
- learn about syndromes of developmental disability and disability principles: see appendix 1
- consider referrals to other clinicians as required (e.g. occupational therapists, physiotherapists, epileptoligists (epilepsy specialist), geneticists, cardiologists and the disability and advisory team in your area)
- engage with adult disability service providers and families to establish working relationships in the healthcare of the young person with developmental disability
- become familiar with the National Disability Insurance Scheme, the role of the clinician in assessment for National Disability Insurance Scheme and the role of the support services in accessing and managing health.

5.3 Being culturally aware

Cultural awareness is a key component in young person-and family-centred care. Being aware of a young person's background and how it will affect their ability to communicate and participate in the care partnership will help to provide better care, care that is empathetic, collaborative, inclusive and ultimately more sustainable. (61) Being culturally aware is the basis of communication between people. It involves the ability to stand back from ourselves and become aware of our own and other people's cultural values, beliefs and perceptions. (61, 62)

Tasmania is culturally and linguistically diverse with people from over 170 countries speaking more than 75 languages (63) and a growing population of people identifying as Aboriginal and Torres Strait Islanders (currently around 20,000). (64)

Young people from a culturally and linguistically diverse background have specific requirements or needs around understanding and accessing health care (63). Cultural differences may create or exacerbate issues such as poverty, poor education or barriers to continuing education, difficulty with transport and poor social support networks; each with the ability to impact the health and wellbeing opportunities of young people (63). These well-documented social determinants of health may mean that young people are not aware of the services available in their community and may not be able to access what is readily available because of language, religion or other cultural barriers. (63)

Transition team members are encouraged to:

- consider completing cultural awareness training
- use the Translating and Interpreting Service (TIS National) if clients have limited English language skills. TIS National provides several services including immediate phone interpreting available 24 hours a day, every day of the year for the cost of a local call. To register, call 131 450
- be aware of health literacy (the knowledge and skills needed to understand and use health information). Health literacy can be an issue for many Tasmanians, particularly those with culturally and linguistically diverse backgrounds
- integrate health literacy strategies into practice and use plain English when communicating with clients. Always assess a young person's health literacy level before providing information and resources. For more information go to: www.dhhs.tas.gov.au/publichealth/health_literacy and www.ceh.org.au
- provide health information for young people in their own language where possible. The following websites contain excellent multilingual resources: www.healthtranslations.vic.gov.au and www.mhcs.health.nsw.gov.au. (61–63)

5.4 Out-of-home care

As at 30 June 2015 there were 1,062 young people in out-of-home care in Tasmania. (65) Out-of-home care is defined as:

> *"overnight care for children aged 0–17 years of age, where the State or Territory makes a financial payment or a financial payment has been offered but declined by the carer"* (66)

The experience of the young person in out-of-home care affects their ongoing care, and the clinician's ability to provide ongoing and transitional support for their chronic condition. This can lead to spasmodic, interventional care and treatment and may have negative effects on the young person's condition and decrease their ability to cope with the changes in their body, condition, care and treatment plans.

Transition team members need to consider:

- young people in out-of-home care often have compromised/fractured access to family and social support
- young people in out-of-home care are at higher risk of:
  - higher levels of mental illness
  - maltreatment and neglect
  - substance abuse
  - low socioeconomic status.

Transition team members are encouraged to:

- be aware of whether the young person is under Custody or Guardianship Orders or temporary out of home living arrangements (e.g. foster care)
- have an understanding of substitute decision-making and guardianship laws; who is able to give permission for the young person
- consider a comprehensive health, psychosocial circumstances and ongoing support assessment such as the HEADSS assessment
- try to maintain consistent clinicians where possible
- assess readiness for transition, which may be delayed or need to occur earlier
- good communication between all parties is essential, including the sharing of records
- complete an electronic health record, while considering privacy and consent.

Further reading

Children, Young Persons and their Families Act 1997
www.dhhs.tas.gov.au/children/child_protection_services/children,_young_persons_and_their_families

Practice point: young people in out-of-home care in southern Tasmania

Young people in out-of-home care in the south have the opportunity to attend the out-of-home care screening clinic at the Royal Hobart Hospital. Young people require a referral from a general practitioner and they will receive an initial comprehensive assessment including dental, behavioural and developmental. Follow up is on an annual basis or earlier if required and for as long as the young person continues under Custody and Guardianship Orders.

It is planned that such a service will soon be available throughout the state.

www.outpatients.tas.gov.au/clinics/paediatric_out_of_home_care_clinic

5.5 Homeless youth

Young people are over-represented in the homeless population but accurate numbers are difficult to determine. It is estimated that there are between 200 and 600 young Tasmanians who are homeless.(67) Young people become homeless for a number of reasons such as: family dysfunction, family violence, alcohol and drug misuse, adverse childhood experiences, family homelessness and mental health problems. These young people are probably also disengaged from health services.

Transition team members need to consider:

- accessing Centrelink schemes and learning about relevant entitlements such as allowances and benefits, health care subsidy systems, hostels
- young people who are homeless probably have compromised/fractured access to family and social support
- young people who are homeless are at higher risk of:
  - higher levels of mental illness
  - maltreatment and neglect
  - substance abuse
  - low socioeconomic status

Transition team members are encouraged to:

- link these young people with services that can assist them in finding housing and support
- link these young people with activities such as youth mental health services
- ensure there is an electronic health record completed

6. Implementation

The *Framework* will be made available to target users by the following avenues:

- publication on the Primary Health Tasmania www.primaryhealthtas.com.au and Tasmanian Health Service websites

In order to assist clinicians in this health space, a suite of resources will be provided to facilitate the transition of young people to adult services.

7. Appendix

Appendix 1 Disability principles

- **Normalisation** – The normalisation principle means making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society
- **Least restrictive principle:** In the health context, his means providing the least invasive treatment to achieve the same medical outcome
- **United Nation Convention of Rights of Persons with Disabilities** – www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
- **Reasonable adjustment:** Means making changes or alterations of usual methods to treat or manage clinical situation to end up with the same standard of care

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