The Sydney children's Hospitals Network
care, advocacy, research, education

TRANSITION AND TRAPEZE

PRACTICE GUIDELINE ©

DOCUMENT SUMMARY/KEY POINTS

- Transition between SCHN and adult health care providers can be a vulnerable time for young people and their families. All clinicians play a key role in supporting the transition of young people to adult services.
- Transition planning can begin from age 14, with supporting self-management, linking in with a GP and identifying appropriate transition pathways. By age 16, the transition plan for the young person should be clear and by age 18 the patient should be transitioned.
- Trapeze can support the transition of patients with complex needs and unclear health transfer pathways.
- This document summarises:
  - Transition to adult care principles
  - The Trapeze Service and key relationships

CHANGE SUMMARY

- Refinement of Trapeze referral criteria
- Inclusion of new processes including Transition Tile, HEEADSSS assessment and prioritisation

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	2nd May 2022	**Review Period:** 3 years
Team Leader:	Manager	**Area/Dept:** Priority Population

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READ ACKNOWLEDGEMENT

- All clinical staff, Clinical Directors and Heads of Departments should read and acknowledge this document.

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Introduction

Adolescents and Transition

Young people are vulnerable when they move between different parts of the health care system. These transitions threaten patient safety which can increase in the possibility of losing critical clinical information, non-adherence to treatment/ poor self-management, and require an increased degree of coordination[1].

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"[2]. This comprises developmentally-responsive support of a young person's emerging independence and self-management, preparation and planning around transfer to adult services, integration with primary health care and consideration of their psychosocial, family and cultural context[3, 4, 5].

Successful transition from paediatric to adult care is an important goal and aims to "maximise lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood"[6]. Education and optimisation of health care and processes during adolescence can yield a triple dividend with immediate benefits, long term benefits and benefits to the next generation.

The transition process focuses on consultation with and preparation of the young person, with the support of their family, general practitioner, specialty teams and other service providers. To ensure that successful transition occurs, each clinical team should develop a transition model for their service that supports young people and families. Structural supports could include providing adolescent specific clinics and wards, transition clinics, joint paediatric and adult clinics, utilisation of transition principles and checklists, and regular collaboration with adolescent and transition services such as Trapeze, or the Agency for Clinical Innovation Transition Care Service. Other supports include individualised transition plans, provision of education and information about transition to adult care and peer support programs[3, 4, 5].

The NSW Youth Health Framework 2017-2024 lists a number of key goals to keep young people in NSW healthy, safe and well:

- Goal 1: the health system responds to the needs of young people, including targeted responses for vulnerable young people
- Goal 2: health services are accessible and young people are engaged and respected
- Goal 3: Young people are supported to optimise their health and wellbeing

Transition is identified as an important component of addressing all three strategic goals with its focus on engaging vulnerable, young people with chronic conditions and supporting their self-management and healthcare access. The Trapeze service works collaboratively with the SCHN Adolescent Medicine to address the Youth Health Framework and provide Adolescent and Young Adult (AYA) services across SCHN. They are supported by a comprehensive research program as part of the Academic Department of Adolescent Medicine (ADAM) and peer support programs such as Chronic Illness Peer Support (ChIPS) and Youth Arts. These services are supported by developmentally appropriate ambulatory spaces with the Centres

for Adolescent and Young Adult Health (CAYAH) Randwick on level 7 in Bright Alliance and the CAYAH Westmead precinct in the E2 space.

Aim

This Practice Guideline provides the framework to plan the transition of young people with a chronic condition into the adult health care system. This includes the timing of transition, the roles of clinical teams and Trapeze and the steps required in transition planning. A range of tools and resources to assist clinical teams in preparing young people for transition is also provided.

Transitioning a patient

1.1 Age of transition

Preparation for transition should generally commence from age 12 years followed by active transition planning from age 16 years. From age 12, all teams have a role in supporting age appropriate individuation and self-management, for example encouraging medication management. Transition planning should be flexible in timing and appropriate to the young person's developmental capacity, starting with the recognition of the important and continuing role of their General Practitioner (GP) and then encouragement of the young person's increasing self-management, balanced with support from their family/carer. Consideration needs to be given to promotion of health literacy as well as assessment of the young person's changing psychosocial needs.

1.2 Admissions Policy

The admissions policy establishes clear guidelines for appropriate age of admission and outpatient clinic care. This is relevant when planning successful transitions involving young people to adult services. Please refer to the Age for admission / treatment: principles regarding inpatient, outpatient, outreach clinic care and clinical research Policy for detailed information around these principles.

SCHN has a transition tile to flag patients around transition age. The tile identifies if the patient is enrolled in Trapeze, has a transition plan and also provides access to relevant forms such as the trapeze referral form and the electronic extension request.

1.3 Transition Models of Care

Transition can be considered by level of complexity:

1. Simple/direct transition of care with equivalent adult services available
2. Complex with multidisciplinary paediatric clinics and scattered adult services
3. Challenging with no adult equivalent services available.

Underpinning these types of transition are seven key principles developed by the Agency for Clinical Innovation (ACI) and Trapeze:

- **i.** A systematic and formal transition process
- **ii.** Early preparation
- **iii.** Empower, encourage and enable young people to self-manage
- **iv.** Identification of a transition coordinator/facilitator
- **v.** Good communication
- **vi.** Individual transition plan
- **vii.** Follow up and evaluation

The principles detail how transition will be undertaken for all young people transitioning their healthcare, including the role of individual team members in transition preparation, the age at which transition will begin and be completed, and the resources to be used to support the process. To facilitate effective transition, treating teams should develop a local transition model for their service, potentially including adolescent specific clinics for patients aged over 12 years and/or at entry to high school.

1.4 Roles during transition

- Treating Clinician/Team: identify barriers to transition and address these. They can encourage self-management where appropriate, provide timely referral to adult services and continue to provide health care until such time as transfer of care is complete. They may see the young person individually, and will provide an individualised transition plan taking into account other factors in the young person's life (e.g. the end of school, age of the young person, and procedures or changes to treatment that may need to be undertaken prior to leaving SCHN). The team can screen for psychosocial needs and refer the young person on to appropriate services.
- General Practitioner (GP): is key in the ongoing coordination of care. This role becomes increasingly important once the young person has left the children's hospital as they provide care coordination and access to specialist and allied health services.
- Trapeze and the ACI Transition Service: appropriately assist with transition planning for complex and challenging transitions. They provide a comprehensive medical/psychosocial transition assessment to guide ongoing support which may include self-management advice, linkage with community support services, support at first adult appointments, guidance around Centrelink and preparation for transition. The Trapeze clinicians work collaboratively with the SCHN clinical teams who remain responsible for the young person's care.

Trapeze

Trapeze is a multidisciplinary transition and care coordination service for the SCHN, supporting young people with complex chronic conditions as they transition from paediatric to

adult health care services. The team assess, facilitate, monitor and coordinate a young person's care during transition and helps the young person live their healthiest lives.

Trapeze works in close collaboration with the ACI Transition Care Service. While Trapeze focus on facilitating transition from the SCHN, the ACI Transition care coordinators help find appropriate health services, provide support to attend clinics and ensure young people stay engaged in adult health services.

Trapeze aims to:

- Understand, support and advocate for the needs of the young person during transition to adult services
- Identify emerging adolescent healthcare needs and support the clinical teams and young person to manage these
- Empower the young person to better manage their chronic health condition as they transition to adult services
- Strengthen the young person's links with their GP and community
- Collaborate with paediatric and adult healthcare teams to provide smooth transition from SCHN
- Support and assist the young person to navigate the health system to improve their engagement with health services
- Keep the transitioning young person well so they can live their healthiest life

Referring to Trapeze

Where additional support is required to facilitate transition and care coordination leading to transition, a young person, carer, SCHN staff member, other healthcare provider or teacher may refer the young person to Trapeze.

Eligibility criteria:

- Aged between 14-25 years, and
- Living with a complex chronic illness currently treated at SCHN, and
- Have an unclear health transfer pathway

Powerchart referrals

Referrals can be completed on SCHN Powerchart. To refer:

Enter patient file – Ad Hoc – Trapeze Service – Trapeze Referral – Chart.

Intake and screening

All referrals are viewed to determine their priority level and transition support needs. The Trapeze prioritisation tool is used to assess referrals during the intake process and prioritise patients into three levels according to medical and psycho-social complexity. Considerations

for triaging referrals include: age, Aboriginal or Torres Strait Islander identification, non-English speaking background, refugee or asylum seeker, out of home care, proximity to hospital (e.g. rural location), upcoming appointments at the hospital, existing wait-lists and complexity of the young person's condition, situation and transition pathway. The amount of assessment, care coordination and follow-up provided is dependent on the priority level the patient has been assigned to.

For the young person who requires transition support, they may be assessed by a Trapeze clinician at either campus of SCHN:

- At a Trapeze multidisciplinary clinic
- At an additional appointment before or after one of their already scheduled appointments (e.g. hospital or school clinic)
- At an outpatient appointment with their usual treating teams
- In hospital, while admitted
- By telephone

Enrolment in Trapeze

After the intake process is undertaken, the young person is either enrolled as an active patient (priority 1 or 2), identified to need minimal transition support (priority 3) or declined.

Enrolled – Active (priority 1 and 2)

These are young persons who have been identified to have multiple transition needs. Depending on complexity and urgency, they will either be identified as a priority 1 or priority 2 patient. They have given verbal consent to be part of the service and for Trapeze to communicate with other health professionals involved in their care. They are enrolled in the service and allocated a clinician who will make further contact to complete a more comprehensive initial assessment.

Enrolled - Minimal transition support needed (priority 3)

These young people have been assessed as requiring minimal transition support due to their younger age, having a well-defined transition pathway with two or less teams involved and limited or no cultural or environmental complexities. This group of young people are given general transition and self-management education and discharged if no further intervention is needed. They will not go on to receive in-depth assessment and management.

Declined

These young persons have indicated they do not want/need any Trapeze assistance or have needs that cannot be supported by Trapeze. They are not enrolled in the service, however are still welcome to contact the service at any time until they are 25 years old. The referring clinician will be informed of this outcome.

Trapeze Assessment and Management

Assessment

For *'enrolled – active'* patients, a comprehensive biopsychosocial initial assessment is undertaken to determine the needs of the young person.

The following areas are discussed:

- Chronic conditions and clinicians/clinics involved
- GP and community involvement
- Capacity and stage of individuation and self-management
- Individual transition plan and transfer of care planning e.g. completion of procedures or treatments while still at SCHN, simple or complex transfer, availability of adult care locally
- Psychosocial /cultural context e.g. financial entitlements, future plans, family and peer support
- Young person's ability for advocacy or problem-solving

From the initial assessment the clinician and the young person and family determine goals and tasks to be allocated and completed. This initial assessment also allows the clinician to determine the level of support that is required from Trapeze.

HEEADSSS

Where appropriate the young person will be asked to complete a HEEADSSS (Home environment, Education/employment, Eating, peer related Activities, Drugs, Sexuality, Suicide/depression, and Safety) psychosocial survey with a prior conversation about privacy and confidentiality, and its limits where there are safety concerns for the young person or another. The survey is available on the TickiT™ platform, and accessible by any internet-enabled electronic device. Please refer to the Digital Psychosocial Screening for Adolescents and Young Adults procedure for more details.

ACI Transition Care Service referral

When the young person has ongoing needs they are referred to the ACI Transition Care Network by a Trapeze staff member. The Trapeze clinician will work in conjunction with the ACI Transition Care Co-ordinator to ensure a smooth transition from paediatric to adult services and remain in contact with treating teams to ensure clear delineation of roles and responsibilities (diagram 1). Trapeze focus on facilitating transition at SCHN, including the preparation for leaving children's services and ACI Care Coordinators help find appropriate adult health services, provide support to attend clinics and ensure young people stay engaged in adult health services. Only patients with greater complexity will be referred to ACI.

Intervention/Follow up

Intervention occurs in the areas of self-management, GP engagement, specialty care engagement, care planning including case conferences, developing transition plans, assisting teams to identify referral pathways and appropriate adult services and addressing psychosocial needs. Trapeze does not assist with NDIS coordination or primary case

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management. Follow up continues until the young person is transitioned and engaged in adult services. The duration of follow up is individualised.

Webinar

Trapeze run regular general transition education webinar via zoom. The webinar covers topics such as how to prepare for transition, what to expect from the adult system, increasing self-management and other psychosocial factors to consider around the time of transition.

The webinar is a one-off and is suited for young people aged 14-17yo and their parents/carers who receive care, or have received care, with the Sydney Children's Hospitals Network. Appropriate participants are considered those who are contemplating transition and would benefit from general education on transition but do not require transition care coordination. This encapsulates, but is not limited to, Priority 3 patients referred to the Trapeze service.

Transfer of Care

The clinician will be in contact with the health care professionals involved in the care of the young person to determine their transfer of care plans. They will ensure referrals are completed and received and first appointments are made.

Trapeze discharge process

Trapeze will consider discharge when the young person is actively engaged in adult health care services. All young people are welcome to contact Trapeze following discharge if they require additional support until 25 years.

Possible indicators of engagement in adult health care include:

- 1 year after leaving SCHN services
- Regularly attending adult health care
- When the young person is older than 20 years of age
- When the young person or parent/carer is confident in their adult health care and able/empowered to coordinate for themselves
- There has been no active support from Trapeze in 1 year

At the point of considering discharge, a Trapeze clinician will conduct a discharge screening questionnaire to ensure the young adult is engaged in appropriate health care services and achieved adult transition to their capacity.

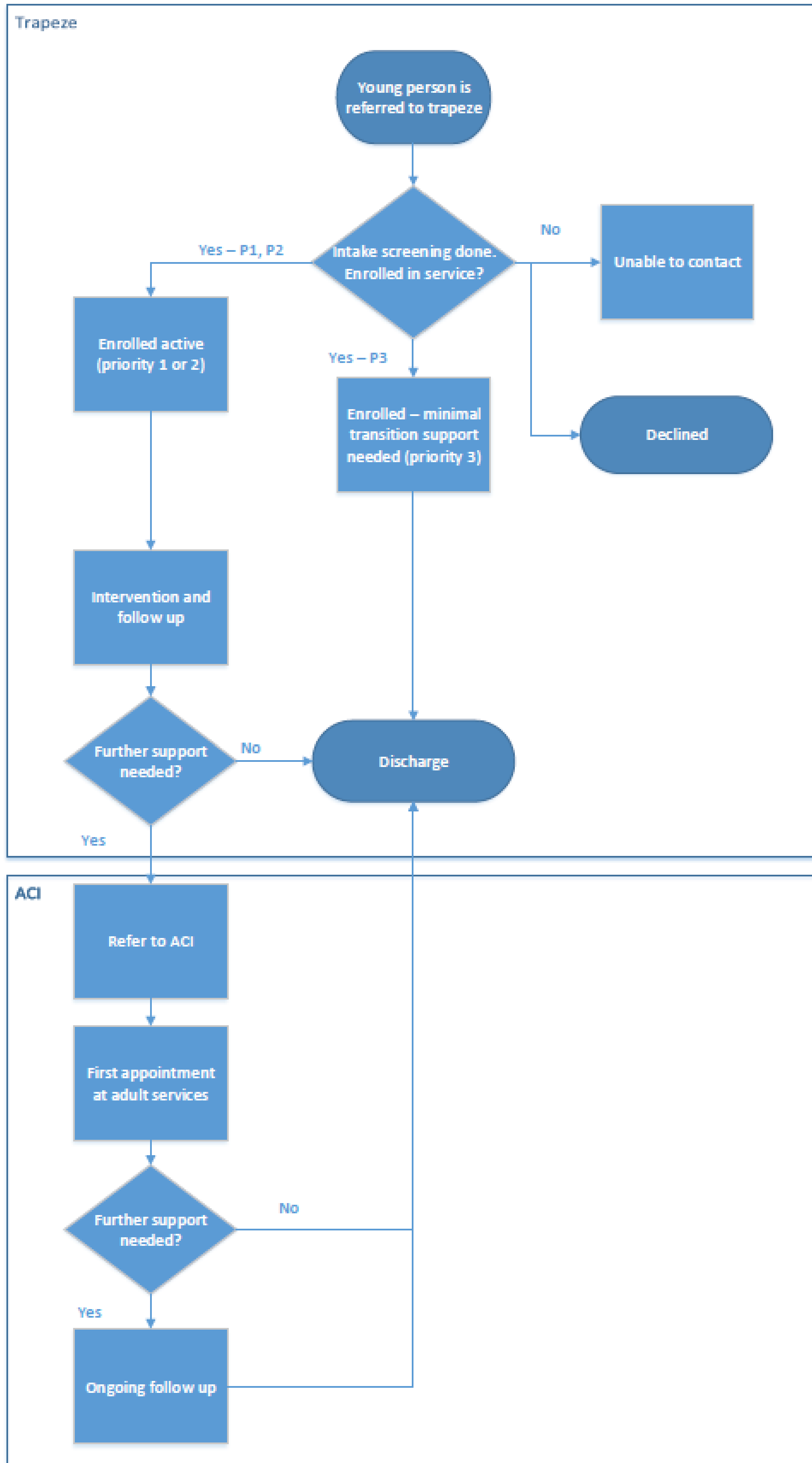

Diagram 1: Trapeze/ACI process

1.5 Resources for transition and self-management

Providing the young person with some prompts may help them identify what needs they have to help them transition. In addition, the transition readiness checklist may help the young person prepare for transition. The individual transition care plan can help the young person and their carer document key contacts and goals of transition. More factsheets and resources can be found on the Trapeze factsheet webpage or on the Trapeze website.

References

1. Culnane E, Loftus H, Peters R, Haydar M, Hodgson A, Herd L, Hardikar W. (2021). Enabling successful transition-Evaluation of a transition to adult care program for pediatric liver transplant recipients. *Pediatr Transplant*. 2021 Dec 30:e14213. doi: 10.1111/petr.14213. Epub ahead of print. PMID: 34967989.
2. Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. A., Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health*, *14*(7), 570-576.
3. Crawford K, Wilson C, Low JK, Manias E, Williams A. (2020). Transitioning adolescents to adult nephrology care: a systematic review of the experiences of adolescents, parents, and health professionals. *Pediatric Nephrology*. 35(4):555-567, 2020 04.
4. Coyne I, Sheehan AM, Heery E, While AE. (2017). Improving transition to adult healthcare for young people with cystic fibrosis: A systematic review. [Review] *Journal of Child Health Care*. 21(3):312-330, 2017 Sep
5. Heery E, Sheehan AM, While AE, Coyne I. (2015) Experiences and Outcomes of Transition from Pediatric to Adult Health Care Services for Young People with Congenital Heart Disease: A Systematic Review. [Review]. *Congenital Heart Disease*. 10(5):413-27, 2015 Sep-Oct.
6. American Academy of paediatrics, American Academy of Family Physicians & American College of Physicians – American Society of Internal Medicine (2002). 'A Consensus Statement of Health Care Transitions for Young People with Special Health Care Needs', *Paediatrics,* 110(6) pp1304-1306, http://pediatrics.aappublications.org/content/110/Supplement_3/1304.short

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