

Supporting Young People During Transition to Adult Mental Health Services

Summary This Guideline supports Local Health Districts and Specialty Networks in developing local policies and protocols that support the optimal transition of young people. In particular, from community-based or inpatient specialist Child and Adolescent Mental Health Service (CAMHS) care or Youth Mental Health Service (YMHS) care to Adult Mental Health Service (AMHS) care.

This Guideline outlines responsibilities of NSW specialist mental health services to ensure continuity of care and safety are maintained during the period of service transition.

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SUPPORTING YOUNG PEOPLE DURING TRANSITION TO ADULT MENTAL HEALTH SERVICES

PURPOSE

Continuity of care is the cornerstone of good clinical practice. Transitional care is recognised as potential risk factors for anyone receiving health care. In the case of young person with mental health issues or challenges, suboptimal transition can lead to disruption of critical developmental milestones and have adverse impacts on their health, social and educational/vocational outcomes.

This Guideline supports local health districts and specialty networks in developing local policies and protocols that support the optimal transition of young people. In particular, from community-based or inpatient specialist Child and Adolescent Mental Health Service (CAMHS) care or Youth Mental Health Service (YMHS) care to Adult Mental Health Service (AMHS) care.

This Guideline focuses on the ongoing health care needs of young people in the context of their evolving and changing developmental needs and pathways to recovery. It outlines responsibilities of NSW specialist mental health services to ensure continuity of care and safety are maintained during the period of service transition.

KEY PRINCIPLES

The following principles are adapted from NICE guidance on transition for young people¹ and the NSW Agency for Clinical Innovation/Trapeze key principles².

- Young people and their families and/or carers are listened to, are engaged in and guide the transition process.
- Service delivery, culture and practice incorporate a recovery focus with an emphasis on hope.
- Young people who are likely to require transition should be identified as early as possible in their contact with CAMHS or YMHS and preparation for transition should be included in early care planning.
- Services work closely together to recognise the developmental stage of the young person and to facilitate a transition process between the services that takes account of the pace that the young person is comfortable with and the need they have for the continued age-appropriate involvement of their family/carers.
- Transition planning and support should be developmentally appropriate and flexible, recognising that the young person's circumstances and autonomy are continuing to evolve.
- Transition planning and support should be strengths-based, using a language of hope, empowering, engaging and enabling young people and their families and/or carers while working towards meaningful goals throughout the transition process.

¹ <https://www.nice.org.uk/guidance/ng43/chapter/Recommendations#overarching-principles>

² http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf

- Transition planning and support should use person-centred approaches with an individualised transition plan for each young person that includes support provided by their family and/or carers, general practitioner, education and other government agencies, Primary Health Networks and other non-government organisations and services providers that are culturally relevant and safe.
- Local CAMHS/YMHS and AMHS should partner in the development and review of transition protocols, communication processes and tools and the identification of transition coordinators/facilitators.
- Young people and their families and/or carers should be involved in service design, delivery and evaluation related to transition and in planning and co-producing transition policies, supporting materials and tools.

USE OF THE GUIDELINE

This Guideline outlines the principles and actions that aim to optimise the outcomes and experiences of young people and their families and carers during periods of service transition. Services are encouraged to develop their own local policies and protocols for the period of service transition for young people.

This Guideline provides a framework and, where available, evidence based guidance to assist NSW Health mental health services to:

- support a safe and effective transition for young people (Section 2)
- manage essential components and phases of transition (Section 3)
- select from a range of evidence informed approaches and implementation resources that support transition (Section 4 and 5)

REVISION HISTORY

Version	Approved by	Amendment notes
GL2018_022	Deputy Secretary, Strategy and Resources	New Guideline.

ATTACHMENTS

1. Supporting Young People During Transition to Adult Mental Health Services: Guideline

**Supporting Young People During Transition to Adult
Mental Health Services**



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1 BACKGROUND

1.1 About this document

This Guideline supports local health districts (LHD) and specialty networks (SN) in developing local policies and protocols that support the optimal transition of young people. In particular, from community-based or inpatient specialist Child and Adolescent Mental Health Service (CAMHS) care or Youth Mental Health Service (YMHS) care to Adult Mental Health Service (AMHS) care.

This Guideline focuses on the ongoing health care needs of young people in the context of their evolving and changing developmental needs and pathways to recovery. It outlines responsibilities of NSW specialist mental health services to ensure continuity of care and safety are maintained during the period of service transition.

The process of supporting transition incorporates joint planning between the treating team and the receiving team so that health care is delivered in an uninterrupted and coordinated manner. Although frequently used interchangeably in everyday practice, the terms 'transitional care' and 'transition' do not hold the same meaning. **Transitional care** in this Guideline refers to the coordination and continuity of care process that starts with preparing a consumer to leave one service and finishes when the consumer is fully engaged in the next service' A similar term 'Transfer of Care' is not used in this this Guideline. **Transition** is a process not an event, requiring a therapeutic intent which ultimately results in established and meaningful engagement of the young person with adult services.^{1,2} Transition in this context is the purposeful, planned movement of young people with moderate to severe mental health issues from CAMHS/YMHS to AMHS or other appropriate services.

This Guideline outlines the principles and actions that aim to optimise the outcomes and experiences of young people and their families and carers during periods of service transition. While the evidence does not identify a preferred model for delivering transitions, it does describe a range of evidence informed approaches that could be considered. Several models are provided in this Guideline as examples.

1.2 The context

Adolescence and young adulthood is a time of developmental change and maturity for young people as they transition towards greater independence. This time includes the development of more mature health behaviours, such as the ability to independently manage aspects of their health and the requirements of treatment, including keeping appointments with health professionals and filling prescriptions. Some young people may require the ongoing support of their families in managing their health for longer periods of time and this may be particularly so for young people with mental health issues, where their development has been disrupted by their experience of illness. The timing of the development of these more mature health behaviours may not correspond with the

¹ Paul, M, Ford, T, Kramer, T et.al. (2013) Transfers and transitions between child and adult mental health services. *British Journal of Psychiatry*, 202, s36-s40.

² Brodie, L and Bridgett, M (2014) *Key Principles for Transition of Young People from Paediatric to Adult Health Care*. Agency for Clinical Innovation and Trapeze, The Sydney Children's Hospitals Network.

expectations of service providers or the expectations or understanding by their families and carers.

Evidence indicates that 50% of lifetime mental illness begins by the age of 14 and 75% by the age of 25, and that 75% of adults who require specialist mental health services developed problems prior to the age of 18.^{3,4} However the dominant health paradigm is that there is delineation between child, adolescent and adult mental health services based on a chronological age. Thus, the peak age for incidence of mental illness coincides with the requirement for young people to move between service structures at a time when it is likely that they are still developing the mature health behaviours that enable them to navigate the change.

Service structures can create an artificial barrier to continuity of care. Careful planning can minimise potential anxiety for the young person and their family and/or carers as they transition from one service to another.

Transitional care is recognised as potential risk factors for anyone receiving health care. In the case of a young person with mental health issues, suboptimal transition can lead to disruption of critical developmental milestones and have adverse impacts on their health, social and educational/vocational outcomes. Providing effective care during transition can help prevent a young person from becoming disengaged with services and assist them to adhere to treatment when there is continuing need, impacting positively on their long term health.

Recent NICE guidance⁵ on transition for young people using health or social care services suggests that poorly managed transitions can also result in deterioration in health and subsequent increased health service costs. Young people who do not transition well are more likely to: fail in attending services; present in crisis resulting in more hospital admissions; and develop avoidable complications. Continuation of care during a positive transition is one of the most important ways to facilitate recovery.

The multicultural and diverse nature of the NSW population translates to potential vulnerability for a large portion of the population.⁶ Services are encouraged to pay particular attention to highly vulnerable young people as they can have an elevated risk for discontinuity of care during this transition period. These groups include young people who are in or transitioning from out-of-home care; are homeless or in unstable housing; transitioning from special education services; are Aboriginal and Torres Strait Islander; culturally and linguistically diverse; refugees or asylum seekers; identify as LGBTI (Lesbian, Gay, Bisexual, Transgender and Inter-sex); and/or those who have chronic illness or an intellectual disability. Young people with severe and profound disability are at high risk of having comorbid mental health issues and are particularly vulnerable

³ Kessler, RC, Berglund, P, Demler, O, et al. (2005), Lifetime Prevalence and Age-of-Onset Distributions of *DSM-IV* Disorders in the National Comorbidity Survey Replication, *Archives of General Psychiatry*;62:593-602

⁴ Kim-Cohen, J, Caspi, A, Moffitt, TE, et al., (2003) Prior juvenile diagnoses in adults with mental disorder: developmental follow-back of a prospective-longitudinal cohort. *Archives of General Psychiatry*, 60, (7), 709–17

⁵ National Institute for Health and Care Excellence (NICE) 2016 Resource impact report: Transition from children's to adult services for young people using health or social care services <https://www.nice.org.uk/guidance/ng43/resources/resource-impact-report-2361777229>

⁶ Oppedal, B, Røysamb, E, Heyerdahl, S. 2005. Ethnic group, acculturation, and psychiatric problems in young immigrants. *Journal of Child Psychology and Psychiatry*, 46:6.

during transitions.^{7,8 910} Young people with neurodevelopmental disorders, emotional/neurotic disorders or emerging personality disorders are also known to be more likely to fall through the gap between CAMHS and AMHS.¹¹

The landmark *Transition from CAMHS to Adult Mental Health Services (TRACK)* study^{12,13} evaluated the process of transition from CAMHS to AMHS, the outcomes in continuity of care and the young peoples' and carers' reports of experiences. The study found that there was a misconception that AMHS are reluctant to accept those young people referred to their services and that good planning and well implemented processes were more likely to result in a positive experience for the young person, preventing them from falling through the gaps in care. The young people themselves reported that having a key professional to help with navigating the transition between CAMHS and AMHS was most important to them. However, for the majority of service users in the study, transition from CAMHS to AMHS was "*poorly planned, poorly executed and poorly experienced*", with very few experiencing a period of parallel care/joint working between CAMHS and AMHS.

Findings and recommendations from the TRACK study, have informed these Guidelines. Please note the four criteria were developed as part of the research, they were not intended as criteria to assess service delivery. They are provided as a guide only.

The four criteria for optimal transition in the TRACK study were:

- a) information transfer (information continuity): a referral letter, summary of CAMHS care, or CAMHS case notes were transferred to AMHS along with a contemporaneous risk assessment;
- b) period of parallel care (relational continuity): a period of joint working between CAMHS and AMHS during transition;
- c) transition planning (cross-boundary and team continuity): at least one meeting involving the service user and/or carer and a key professional from both CAMHS and AMHS prior to transfer of care;
- d) continuity of care (long-term continuity): the young person was either engaged with AMHS three months post-transition or appropriately discharged by AMHS following transition.

7 Brodie, I, Goldman, R and Clapton, J. (2011) Mental Health Service Transitions for Young People. Social Care Institute for Excellence Research, Briefing 37. <http://www.scie.org.uk/publications/briefings/briefing37>

⁸ Australasian Faculty of Rehabilitation Medicine The Royal Australasian College of Physicians, (2014) Transition of Young People with Complex and Chronic Disability Needs from Paediatric to Adult Health Services.

9 Oppedal, B, Røysamb, E, Heyerdahl, S. 2005. Ethnic group, acculturation, and psychiatric problems in young immigrants. *Journal of Child Psychology and Psychiatry*, 46:6.

¹⁰ Martel, Adele, and D. Catherine Fuchs. "Transitional Age Youth and Mental Illness-Influences on Young Adult Outcomes." *Child and adolescent psychiatric clinics of North America* 26.2 (2017): xiii.

¹¹ Singh, S, Paul, M, Ford, T, et al. (2010) Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study. *British Journal of Psychiatry*, 197, 305-312

¹² Singh, SP, Paul, M, Islam, Z, et al. (2010) Transition from CAMHS to Adult Mental Health Services (TRACK): A Study of Service Organisation, Policies, Process and User and Carer Perspectives: Report for the National Institute for Health Research Service Delivery and Organisation Programme., Queen's Printer and Controller of HMSO.

http://www.nets.nihr.ac.uk/data/assets/pdf_file/0010/64288/FR-08-1613-117.pdf

¹³ Singh, SP, Paul, M, Ford, T, et al. (2008) Transitions of care from child and adolescent mental health services to adult mental health services (TRACK study): a study of protocols in Greater London. *BMC Health Service Research* (8) 1-7.

1.3 Legislative and policy framework

The development of this Guideline has been informed by key aspects of NSW legislation, government policy and plans.

This Guideline should be read in conjunction with the following NSW Health policies:

- PD2016-056 *Transfer of Care from Mental Health Inpatient Services* sets out the principles and requirements for safe transfer of a mental health consumer's care across health settings. This policy is under review as of May 2018.
http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2016_056.pdf
- PD2009_060 *Clinical Handover–Standard Key Principles* identifies the standard set of key principles for all types of clinical handover.
http://www0.health.nsw.gov.au/policies/pd/2009/PD2009_060.html
- PD2011_016 *Children and adolescents with mental health problems requiring inpatient care* http://www0.health.nsw.gov.au/policies/pd/2011/PD2011_016.html
- *NSW Health Privacy Manual for Health Information* (March 2015)
<http://www.health.nsw.gov.au/policies/manuals/Documents/privacy-manual-for-health-information.pdf>
- PD2006_053 *Interpreters - Standard Procedures for Working with Health Care Interpreters*
http://www1.health.nsw.gov.au/PDS/pages/doc.aspx?dn=PD2006_053
- PD2010_073 *Youth Health Policy 2011-2016: Healthy bodies, healthy minds, vibrant futures*
http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2010_073.pdf
- PD2017_025: *Engagement and Observation in Mental Health Inpatient Units*
http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2017_025.pdf

Relevant Legislation includes:

- *Privacy and Personal Information Protection Act*
<https://www.legislation.nsw.gov.au/#/view/act/1998/133>
- *Health Records and Information Privacy Act 2002*
<https://www.legislation.nsw.gov.au/#/view/act/2002/71>
- *Mental Health Act 2007*
<http://www.health.nsw.gov.au/mhdao/Pages/legislation.aspx#mh-act-2007>
- *Children and Young Persons (Care and Protection) Act 1998*
http://www.austlii.edu.au/au/legis/nsw/consol_act/caypapa1998442/

Other informing documents include:

- Brodie, L and Bridgett, M (2014) *Key Principles for Transition of Young People from Paediatric to Adult Health Care*. Agency for Clinical Innovation and Trapeze, the Sydney Children's Hospitals Network.
http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf
- National Institute for Health and Care Excellence (NICE) (2016) *Transition from Children's to Adults' Services for Young People Using Health or Social Care*

Services. National Institute for Health and Care Excellence, NG43

<https://www.nice.org.uk/guidance/ng43>

- Australian Commission on Safety and Quality in Health Care (2012) *National Safety and Quality Health Service Standards (September 2012)* ACSQHC, Sydney. <http://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf>
- Commonwealth Department of Health (2010) *National Standards for Mental Health Services 2010*, Commonwealth of Australia, Canberra. [http://www.health.gov.au/internet/main/publishing.nsf/content/CFA833CB8C1AA178CA257BF0001E7520/\\$File/servst10v2.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/CFA833CB8C1AA178CA257BF0001E7520/$File/servst10v2.pdf)
- Victorian Government, Department of Health (2013) *National Practice Standards for the Mental Health Workforce 2013*. Victorian Government Department of Health, Melbourne, on behalf of the Safety and Quality Partnership Standing Committee. <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-wkstd13>
- NSW Health (2011) *NSW Child and Adolescent Mental Health Services (CAMHS) Competency Framework*. NSW Ministry of Health, Sydney. <http://www.health.nsw.gov.au/mhdao/programs/mh/Publications/camhs-nov11.pdf>
- Commonwealth Department of Health (2013) *A National framework for recovery-oriented mental health services: guide for practitioners and providers*. Commonwealth of Australia, Canberra <http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-n-recovgde>
- Framework for Suicide Risk Assessment and Management for NSW Health Staff <http://www.health.nsw.gov.au/mentalhealth/programs/mh/Publications/framework-suicide-risk-assess.pdf>
- PD2007_059 Aboriginal Mental Health and Well Being Policy 2006-2010 http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2007_059.pdf
- PD2008_067 Multicultural Mental Health Plan http://www1.health.nsw.gov.au/pds/ActivePDSDocuments/PD2008_067.pdf
- Connecting with Carers Is Everybody's Business: A training resource for family friendly mental health services <http://www.health.nsw.gov.au/mentalhealth/publications/Publications/pub-connecting.pdf>

1.4 Key definitions

AMHS refers to Adult Mental Health Services.

CAMHS refers to Child and Adolescent Mental Health Services.

Carer in this document, 'carer/s' refers to a designated carer and /or a principal care provider as defined under the Mental Health Act 2007.

Consumer in this context refers to a person under the care of a NSW Local Health District/Specialty Network Mental Health Service.

Continuity of care involves a consistent, connected and coherent approach that is responsive to the consumer's health needs and personal context.

Recovery means gaining and retaining hope, understanding of one's abilities and disabilities, engagement in an active life, personal autonomy, social identity, meaning and purpose in life, and a positive sense of self.

Transition in this context is the purposeful, planned movement of young people with moderate to severe mental health issues from CAMHS/YMHS to AMHS or other appropriate services.

Transitional care in this Guideline refers to the coordination and continuity of care process that starts with preparing a consumer to leave one service and finishes when the consumer is fully engaged in the next service' A similar term 'Transfer of Care' is not used in this this Guideline.

YMHS refers to specialist Youth Mental Health Services for 14 to 24 year olds.

2 SUPPORTING A SAFE AND EFFECTIVE TRANSITION

2.1 Continuity of care

Continuity of care is the cornerstone of good clinical practice¹⁴. Mental health care for young people in NSW is delivered across a spectrum of care from school based and primary care mental health services through to specialist mental health services. Not all young people being provided a service in CAMHS or YMHS will need to transfer to AMHS for their ongoing mental health care. Some young people may be better served through primary health care, non-government services, school-based, private health care and/or other service systems. The continuity of a general practitioner or primary health care provider should be encouraged for all young people at all times, including periods when they are receiving specialist services from CAMHS, YMHS or AMHS.

2.2 Key decision making factors

In decision making, mental health services are required to balance the needs, preferences and choices of the young person and their families with the available infrastructure and resources. In making decisions regarding the transition of care to adult services, transition should not be rigidly determined by age alone, consideration should be given to the developmental stage, severity and complexity of condition and degree of risk. The decision is also contingent on the availability of services and the capacity of the young person, family and/or other carers to access them. Cultural needs should also be considered.

When assessing a young person for transition, a range of care options should be considered. The assessment should take into account the wider context of the young

¹⁴ Australian Commission on Safety and Quality in Healthcare (2012) *National Safety and Quality Health Service Standards* (September 2012). ACSQHC, Sydney

person's life such as cultural identity, education, employment, family and carer supports, housing, access to transport and supports, the community environment, particular risks and anxieties that may arise for a young person with a history of trauma and other transitions happening in the young person's life at that same time. This context is particularly relevant for young people in out-of-home care and who may also be transitioning from longer term/existing supports such as school or paediatric disability services.

Clinicians may need to take special note of young people at risk of falling through the gap in services during transition (particularly those vulnerable populations identified earlier) and put safeguards in place such as an agreed safety plan for early warning signs to support a smooth transition. Services should consider the needs of young people as well as their families and carers during transition.

The transition from CAMHS to YMHS and/or to AMHS requires increasing autonomy on the part of the young person, reflected in the change in the nature of service delivery from a family-oriented system to a person-oriented system. The developmental stage of the young person should be taken into account in determining the type of care system that will best suit their needs and support the best recovery outcomes. Also, the boundaries of "family" are not universally shared across all persons in NSW. For 32% of NSW school students, individuation and adolescent autonomy have different implications and pathways than may be presumed by conventional service planning, which can lead to increased morbidity yet remain unrecognised.¹⁵ All services are encouraged to support self-determination and choice on the part of the young person, but to recognise that not all youth may be at a point, developmentally, where they can effectively manage their own care. In these circumstances, families and carers may need to be more involved in their young person's care for a period of time.

2.3 Principles for transition

The following principles are adapted from NICE guidance on transition for young people¹⁶ and the NSW Agency for Clinical Innovation/Trapeze key principles¹⁷.

- Young people and their families and/or carers are listened to, are engaged in and guide the transition process.
- Service delivery, culture and practice incorporate a recovery focus with an emphasis on hope.
- Young people who are likely to require transition should be identified as early as possible in their contact with CAMHS or YMHS and preparation for transition should be included in early care planning.
- Services work closely together to recognise the developmental stage of the young person and to facilitate a transition process between the services that takes account of the pace that the young person is comfortable with and the need they have for the continued age-appropriate involvement of their family/carers.

¹⁵ Li, Yong. 2014. Intergenerational conflict, attitudinal familism, and depressive symptoms among Asian and Hispanic adolescents in immigrant families: A latent variable interaction analysis. *Journal of Social Service Research*, Vol 40(1)

¹⁶ <https://www.nice.org.uk/guidance/ng43/chapter/Recommendations#overarching-principles>

¹⁷ http://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf

- Transition planning and support should be developmentally appropriate and flexible, recognising that the young person's circumstances and autonomy are continuing to evolve.
- Transition planning and support should be strengths-based, using a language of hope, empowering, engaging and enabling young people and their families and/or carers while working towards meaningful goals throughout the transition process.
- Transition planning and support should use person-centred approaches with an individualised transition plan for each young person that includes support provided by their family and/or carers, general practitioner, education and other government agencies, Primary Health Networks and other non-government organisations and services providers that are culturally relevant and safe.
- Local CAMHS/YMHS and AMHS should partner in the development and review of transition protocols, communication processes and tools and the identification of transition coordinators/facilitators.
- Young people and their families and/or carers should be involved in service design, delivery and evaluation related to transition and in planning and co-producing transition policies, supporting materials and tools.

3 MANAGING TRANSITION

The process of transition needs to be negotiated between the current treating team and the receiving clinical team in a planned and coordinated way with timely exchange of information. There is an expectation that the young person and their family and carers will be consulted. The receiving team will then be better equipped to understand what has worked well and what hasn't worked so well for each young person and their family and/or carers. The young person and their family and/or carers should also be provided with support in preparation for the transition to the new service.

3.1 Essential components of transition

To achieve optimal transition, the following components of good practice should be considered and applied whenever possible:

- clinicians listen to, actively engage and are guided by the young person and their family and/or carers
- information and choice (where possible) is offered to the young person and their family/carers to assist them in the decision making, preparation and transition process
- the receiving care team is engaged well in advance of the time of transition with CAMHS and YMHS clinicians continually assessing engagement with AMHS
- the transition is carefully negotiated and planned with clear information provided from the referring CAMHS/YMHS to the receiving AMHS
- the treating CAMHS/YMHS team remains involved with the young person and family where appropriate, in collaborative care and joint working for a period of time to support the transition

- appointing a dedicated transition worker or consistent designated professional to assist the young person and their family to navigate the transition process within both CAMHS/ YMHS and AMHS
- multiple simultaneous transitions to a range of other agencies are avoided, so that the young consumer maintains maximum stability of service and relationship throughout the period to support them through transition

3.2 Phases of transition

The following section outlines four phases of transition: *transition planning, support before transfer; support during transition and support after transfer.*

3.2.1 Transition planning

Operationalising transition planning¹⁸ includes:

- early planning
- an identified professional to coordinate transition
- opportunities for involving young people such as peer support, coaching and mentoring, advocacy and the use of mobile technology
- using a range of communication tools
- supporting independence
- involving parents and carers with appreciation of the diverse roles and responsibilities they have in a multicultural society

Services are encouraged to involve other relevant services and agencies in the transition planning. For example, if the young person is receiving other specialist services such as mentoring services or substance abuse treatment, or support from education and other government agencies, Primary Health Networks and other non-government organisations and service providers, then the relevant services if ongoing are included in transition planning.

Part of transition planning should include providing young people and their families with information on what the new service alternatives offer, to assist choice and self-determination. Explaining service offerings will also prepare young people and their families with what to expect once a choice has been made and referral has been accepted. This would include an understanding of the roles and responsibilities of each partner service during the transition period.

With the increasing involvement of Primary Health Networks and Community Managed Organisations (CMO) in mental service delivery, services need to be familiar with when the client is likely to be transitioning within the public mental health system and when they will be transitioning to CMO services, and have established pathways and partnerships with key CMO referral destinations.

¹⁸ <https://www.nice.org.uk/guidance/ng43/chapter/recommendations#transition-planning>

Transition readiness

Care transition of adolescents with chronic health conditions may be more challenging when the young person has not acquired the necessary skills and developmental milestones. It is therefore important for health care providers to assess the readiness for transition of their adolescent clients. In combination with effective assessment and clinical decision making, consideration could be given to the use of transition readiness tools. A number of tools have been developed to help determine the readiness of the young person to transition to adult services and are freely available. A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic illness found the Transition Readiness Assessment Questionnaire (TRAQ) had the most robust properties (Appendix 1)¹⁹. The TRAQ tool is illness-neutral and not specific to mental health clients.

Clinical judgement should be used before giving it to young clients, as the tool may not be appropriate for some young mental health clients. For example, the involvement of family or carer in assisting in the young client's care is often a feature of optimal care rather than a deficit in transition readiness. The tool could still be useful however in guiding the clinician's assessment of the client's particular profile of needs.

The main variables for assessing readiness include:

- managing medications
- appointment keeping
- tracking health Issues
- talking with providers
- managing daily activities

If the young person has difficulty with any of the readiness variables, the transition phase may need to be extended and supports may need to be put in place to effect an optimal transition. As part of good practice, CAMHS or YMHS should also start working on those specific variables whilst the young consumer is still in their care.

Transition protocols

Services are encouraged to develop local transitions protocols. While necessary in communicating shared expectations and responsibilities, protocols on their own are not sufficient for effecting appropriate and adequate transitions. A recent report commissioned by the Mental Health Commission of Canada ²⁰ *Taking the Next Step Forward — Building a Responsive Mental Health and Addictions System for Emerging Adults* cautions that a simple over-emphasis on transfer protocols and 'connecting the dots' is limiting in comprehensively addressing the issues for young people moving from youth to adult services.

¹⁹ Zhang LF, Ho JSW, Kennedy SE (2014). A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatrics* 2014, 14:4

²⁰ Mental Health Commission of Canada. (2015) *Taking the Next Step Forward: Building a Responsive Mental Health and Addictions System for Emerging Adults*, Mental Health Commission of Canada, Ottawa.
<http://www.mentalhealthcommission.ca/English/system/files/private/document/Taking%20the%20Next%20Step%20Forward.pdf>

3.2.2 Support before transfer

Operationalising support before transfer ²¹ includes:

- contingency plans to provide consistent transition if an identified transitional professional leaves their position
- creating a personal folder with the young person to share with adults' services
- preparing information for young people and families/carers on what to expect from services and what support is available to them. For example, individuals with severe mental health disorders likely to need hospitalisation may benefit from orientation to processes around adult inpatient hospitalisation

3.2.3 Support during transition

It is good practice to involve families and carers in transition planning and support where possible. The *Mental Health Act 2007* recognises the role of carers in supporting people with a mental illness or mental disorder and includes specific provisions that set out when a carer should be informed or consulted about particular aspects of a person's care or treatment (see Chapter 4 of the Mental Health Act Guidebook for further information). The TRACK study reported that parental involvement increased the chances of successful transition. Families have reported feeling left out of the process, which created confusion and anxiety for them about the transition. Potential anxiety can be minimised by good planning and joint working between the young person, their family, carers and professionals.

It is important to balance the young person's need for autonomy and decision-making rights with the desires and continued role of family members. Competency to make independent decisions varies greatly in this population and across cultures. Many young people in transition still require continued support and resources (e.g. housing, finances) from family.

Parents and other caregivers are often the core support for a young person and need to be involved, informed, and supported. Issues of confidentiality need to be addressed with consideration with explicit agreements with consumers and carers about what information should be shared. Professionals need specific capabilities, as well as a willingness to address, mediate and support all parties through the struggle between autonomy and dependency. The services may consider seeking guidance from the young person about how they want their families to be involved. There are some times when it may not be appropriate to involve families and/or carers, however their own mental welfare and the potential for traumatising the family by excluding them needs to be considered. Some young people requiring transition may be living independently and/or estranged from their family. If family or carers cannot be involved, then more support for the family members themselves from the transitioning services and the CMO or other sectors may need to be considered. Families and carers should not be excluded from vital areas that they had been supporting and which are not going to be addressed by Health or other services if the consumer is not competent to look after them independently e.g. housing. Such exclusion without provision of external support constitutes an increase in risk for the young consumer.

²¹ <https://www.nice.org.uk/guidance/ng43/chapter/recommendations#support-before-transfer>

Engagement framework

Motivational issues and stages of change are significant factors in service discontinuance with this population. This area can be addressed by thoughtful and evidence-based engagement practices.

The presence of peers has been shown to support successful transitions and maximises the probability of continued engagement or first-time connection with AMHS. Peer connections complement the role of parents to offer motivation to begin, continue, or discontinue an activity. An engagement framework for transitioning young adults could include support for the development of peer connections, including mentors, peer support groups, and peer support worker roles. This approach could also include supporting the young person to maintain contact with their peers through engagement in education/vocation, through technology or involvement in local activities.

Using a person-centred future planning approach is shown to be more likely to engage young people in the transition process. Staff who believe in young peoples' abilities and respect their views and goals are more likely to focus on building on their strengths. Young people benefit from staff providing them with pro-social activities and connecting them with opportunities such as volunteering, internships, and work on community projects, so that youth learn that they can make positive contributions to society.

Communication and documentation of the process

Clear information about the transition, including the transition plan and information about the receiving team's service should be provided to the young person and their family or carer. The evidence suggests that young people value information which is:

- given both verbally and reinforced in writing
- is appealing to them and jargon free
- describes what to expect
- defines the roles and responsibilities of clinicians in transition
- prepares them for the transition

Clear, effective and timely communication between all relevant stakeholders is critical to the success of the transition process. Documentation is part of the systematic and formal transition communication process. The development of an individual transition plan should be developed with the young person and communicated to receiving agencies and key service partners in a developmentally appropriate manner. It should be reiterated that this is a dynamic process and any 'transition plan' document, a copy of which should also be held by the young person and ideally, their family or carer, does not represent the whole transition planning process.

Communication in relation to the transition process should include the following:

- the needs of the young consumer and the needs and role of the informal support network (family, carers, friends and peers);
- introduction of the young person to the receiving service and their key contact in advance of the transition;

- sensitivity and responsiveness to the needs and preferences of Aboriginal and Torres Strait Islander people thereby ensuring that the transition process is conducted in a culturally secure way;
- alternatives to meet the needs and preferences of people from culturally and linguistically diverse backgrounds;
- all stakeholders relevant to the transition process, including family and/or carers where appropriate, are identified and a system for communication between all parties is established;
- all team members involved in the process need to be made aware of their delegated responsibilities for various parts of the transition process; and
- all communication and information shared as part of the transition process and the transition plan are documented in the young person's clinical record
- services would also exchange documentation as appropriate during a transfer of care.

Managing risk during the transition process

For young people with mental health issues or challenges, the transition from adolescence to adulthood is made even more difficult as developmental milestones may not have been met due to their illness. Multiple transitions may also be co-occurring. These factors can make transition a challenging time which may precipitate a crisis for some young people.

It is important therefore to be aware of early warning signs of distress in the young person. The individual warning signs should be discussed with the young person and their family and carers and documented in the transition planning. A protocol for communicating around deterioration of increasing risks should be agreed. The treating team along with the receiving team, as part of the transition plan, should develop a safety plan to mitigate the risk across the period of transition. Both teams should undertake a combined review of the safety plan at the beginning of the process and when care is finally transferred.

Risks may also be minimised if the referring service which has an established relationship with the young person and is likely to be aware of triggers, signs of distress and helpful interventions, maintains contact with the young person, their family/carer (as appropriate) and the receiving service for an agreed settling-in period. The contact may then be reduced as agreed between all who are parties to the plan. The referring service is likely to know the young person well and can provide invaluable information to the referring service on how best to understand and work with the young person and their family/carer needs.

3.2.4 Support after transfer

Ensure continuity of care in adults' services after transfer. For example, an identified case manager or transition worker within the adult mental health service should continue to follow-up the young person for an appropriate period of time following transition. Also,

services should take active steps if the young person does not attend appointments or engage with adults services.²²

Monitoring outcomes

For individual young people and families

Monitoring the outcomes of the transition process can provide both transferring and receiving services important information to use in service improvement as well as ensuring that goals for consumers have been achieved.

For services

Services may wish to monitor aspects such as: whether all actions agreed and outlined in the transition plan were completed; whether the young person engaged with the receiving services and remained engaged for the expected time period; whether the young person and their family's experience of the transition process was positive; and so on.

The Your Experience of Service (YES) survey may be helpful consumer feedback to Local Health District and Specialty Network mental health services on the experiences of transition-aged youth attending local services.

The Social Care Institute for Excellence *Mental Health Service Transition for Young People* website provides practice examples, including an example of auditing a transition protocol.²³

4 MODELS OF TRANSITION SERVICE STRUCTURE

While the evidence does not identify a preferred model for delivering transition services, it does indicate that there is a range of approaches which may be complementary rather than being mutually exclusive. The broader mental health system and local circumstances should be considered in developing a transition model. While understanding that not all young people will require transition from CAMHS to AMHS, this section will focus on several models that may be considered.

There is no single service model that fits the needs of all young people requiring transition from CAMHS to AMHS. In Local Health Districts where cultural diversity exists, this matter should be specifically addressed in planning and service delivery, involving relevant professional development and clinical resources.

The service transition process is individual in nature, dependent on the mental health problem, the individual characteristics of the young person and their families or care givers and their histories and availability of local resources. The transition model selected should deliver a range of recommended evidence-informed interventions referred to in other sections of this guideline and one that best suits the capacity of the service to meet the demands of the population. The model should also include reciprocal agreement

²² <https://www.nice.org.uk/guidance/ng43/chapter/recommendations#support-after-transfer>

²³ <http://www.scie.org.uk/publications/guides/guide44/practiceexamples/oxfordshire.asp>

structures between CAMHS and AMHS to ensure roles and responsibilities are clearly articulated.

Irrespective of the model selected, young people have identified that they want access to a consistent designated professional to assist them to navigate the transition. Young people also identified the value of peer support during the transition phase²⁴. The literature identifies a number of different models for structuring services to optimise transition between CAMHS and AMHS, which are described below.

4.1 Transition clinics or services

These clinics are based on a shared management framework, which develops partnerships between a range of providers broader than CAMHS and AMHS (e.g. with GPs). Typically, these clinics operate out of joint locations; however there are some examples of stand-alone transitional clinics that interface with youth and adult services.

An example of this is the Trapeze²⁵ service at Sydney Children's Hospital Network that was established as a service to support young people with chronic health conditions as they transition from paediatric to adult services. Trapeze offers comprehensive care coordination services that are practical, timely and relevant to the young person's needs. The service supports the young person and their family to develop stronger links with their GP or medical specialist, provides telephone support, and facilitates care coordination and navigation of the health system while also providing health coaching.

The NSW Agency for Clinical Innovation's Transition Network aims to improve the continuity of care for young people aged between 14 – 25 years of age with chronic health problems and disabilities as they move from children's health services to adult health services. The network which has three Transition Care Coordinators extends across all local health districts in NSW and works closely with Trapeze. Coordinators provide support and coordination to assist young people to navigate the health system and take more responsibility for the health care. More information can be found on the website <https://www.aci.health.nsw.gov.au/networks/transition-care>

Transition Teams

Transition Teams are based on a shared management model and can lead to better coordination of care and can foster collaboration between the CAMHS and AMHS teams. In this model, a specific team is set up to manage transitions. Teams are made up of transition coordinators who can be funded from both CAMHS and AMHS. The team is responsible for the planning and coordination of the transition process. They are also responsible for the clear and regular communication between all stakeholders.

It is preferable for an Aboriginal Mental Health Clinician or trainee to assist in the transition process for Aboriginal and Torres Strait Islander young people. The young person and their family would also need to be made aware of Aboriginal Mental Health

²⁴ Sainsbury M & Goldman R.(2014): *Mental health service transitions for young people*. Children's and Families Services Guide 44, Social Care Institute for Excellence, Great Britain.

²⁵ www.trapeze.org.au

Clinicians or trainees that are available to provide care and support in the receiving service to assist the young person's choice of ongoing service provider.

4.2 Key transition coordinator/facilitator

The transition coordinator/facilitator could be a clinician who bridges CAMHS and AMHS and manages a small number of people at a time to facilitate the transition between the child and adolescent and the adult mental health systems.

There are a number of ways that this can be done, for example:

- by a joint post;
- by a designated staff member who is trained in working with young people seconded to an adult service; or
- having a clinician from the referring multidisciplinary team designated to take responsibility for the transition. This approach also requires a key worker from the receiving team to be identified and included in the process.

The TRACK study found that designated transition workers who worked across CAMHS and AMHS were highly successful in delivering a smooth transition.

A transitional coordinator/facilitator may also not need to be employed in a designated position or role or be responsible for managing multiple simultaneous transitions. The most important component is that a key set of functions for transition are carried out by a staff member who takes the lead. The functions could include:

- act as a single point of contact for the young person and their family or carer;
- coordinate the delivery of actions agreed according to the transition plan;
- monitor and review the transition plan; and reduce overlap and inconsistency in the services received; and
- monitor the outcomes of transition and make recommendations for service improvement if required.

Irrespective of the model and job title, having a consistent designated professional to assist the young person and their family to navigate the transition process is the key to any of the models working effectively. If dedicated resources are unavailable to set up specific transition teams or to employ transition coordinators, then clinicians within the service should be given the skills and time to assist young people during transition, supported by clear local protocols and practices.

5 IMPLEMENTATION RESOURCES

NICE includes guidance on aspects of transition that may be challenging to implement²⁶, including actions that managers and clinicians can take to support:

- services taking joint responsibility for transition
- joint planning, development and commissioning of services involved in transition

²⁶ <https://www.nice.org.uk/guidance/ng43/chapter/Implementation-getting-started>

- improving front-line practice through training in developmentally appropriate services and person-centred practice
- maximising opportunities for young people who have become disengaged or who are not eligible for adult services to access appropriate care and support

The NICE Baseline Assessment Tool ²⁷ can also be downloaded from the NICE resources and used in conjunction with the NICE guideline to support local implementation.

*Key Principles for Transition of Young People from Paediatric to Adult Health Care*²⁸, developed by the NSW Agency for Clinical Innovation and Trapeze at the Sydney Children’s Hospitals Network, also contains operational advice that can inform local mental health protocols and practice in NSW Local Health Districts and Specialty Networks.

The Health Education and Training Institute Mental Health Workforce Development portal provides NSW Health clinicians with a wide range of resources including “Improving Transitional Mental Health Services for Youth” by Professor Simon Davidson from Canada. Please click on this link to register: <http://mhwfd.heti.edu.au/login/signup.php>

The comprehensive MILESTONE Project²⁹ is currently underway across eight European Union (EU) countries. Under the leadership of Professor Swaran Singh, the MILESTONE Project aims to strengthen the evidence-base to improve transition experiences for young people from CAMHS to AMHS and it is expected that this project will inform continuing improvements across NSW Health as the results emerge. The MILESTONE work packages will:

- map current services and transitional policies across the EU
- develop and validate transition-specific outcomes measures; conduct a longitudinal cohort study of transition process and outcomes across eight EU countries
- develop and test, in a cluster-randomised trial, the clinical and cost-effectiveness of an innovative transitional care model
- create clinical, organisational, policy and ethics guidelines for improving care and outcomes for transition age youth
- develop and implement training packages for clinicians across the EU. Please click on this link for resources: <https://www.nice.org.uk/guidance/ng43/resources>

²⁷ <https://www.nice.org.uk/guidance/ng43/resources>

²⁸ Brodie, L and Bridgett, M (2014) *Key Principles for Transition of Young People from Paediatric to Adult Health Care*. Agency for Clinical Innovation and Trapeze, The Sydney Children’s Hospitals Network.

²⁹ <http://www.milestone-transitionstudy.eu/>

6 APPENDICES

6.1 Appendix one: Sample transition readiness tool

Transition Readiness Assessment Questionnaire (TRAQ)

Directions to Youth and Young Adults: Please check the box that best describes **your** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighbourhood stores and services (For example: Grocery stores and pharmacy stores)?					

Directions to Caregivers/Parents: If your youth or young adult is unable to complete the tasks below on their own, please check the box that best describes **your** skill level. **Check here** if you are a parent/caregiver completing this form.

Ref: <http://www.etsu.edu/com/pediatrics/traq/>