Strategy in Action Meeting

Care pathways for young people in the transition age group (16-25yo)

NEDC acknowledges Traditional Custodians of Country throughout Australia we recognise the continuing connection to land, water, and community. We pay our respect to Aboriginal and Torres Strait Islander cultures and peoples; and to Elders past and present.
Sovereignty was never ceded.

NEDC acknowledges the individual and collective contributions of those with a lived and living experience of eating disorders, and those who love, have loved and care for them to both influence and drive change in the stepped system of care.

Each person's experience is unique, and we value and uphold lived experience leadership and contribution in improving the system of care for people impacted by eating disorders.

Session roadmap

11:00 am   **Welcome & Acknowledgments**

11:05 pm   **The Context**

Framing the challenge from a development and systemic perspective

11:20 pm   **Sharing the Challenge**

Outlining of system and services challenges

11:55 pm   **Break**

12:00 pm   **Finding Solutions**

Problem solve together alternate solutions to address the pre-identified service and system challenges.

1:00 pm   **Close**

Actions and Outcomes

'Sprint group meetings' will focus on complexities and shared barriers for our colleagues and stakeholders on specific topics that align with the National Strategy.

- Setting the scene: What is the context?

- Summarise the literature

- Reflect on the challenges

- Share ideas

- Identify solutions

- Create relationships

- Understand the young person's journey

- Understanding the barriers to care

- Awareness of possible solutions

- Intention for future work

- Relationships are created

- Post summary of discussion

Who is here?

- Royal Children's Hospital
- Orygen Youth Health
- Royal Melbourne Hospital
- Grampians Health
- Queensland Eating Disorder Service
- Children's Health Queensland
- Westmead
- Monash Health
- Alfred Health
- Northern Territory Health

- Tasmanian Eating Disorder Service
- NT Anglicare
- Austin Health
- Perth Children's Hospital
- WAEDOCS
- ACT ED Hub
- CEED
- Central Australian Aboriginal Congress
- NSW Statewide Eating Disorder Service
- Gold Coast University Hospital

It's a big group…

- Solution focused, judgement free

- NEDC facilitates discussion

- Microphones off unless speaking

- Hands up

- Please introduce self when speaking

- Use the chat function to provide ideas, suggestions, links

- Your role: observer, questioner, speaker

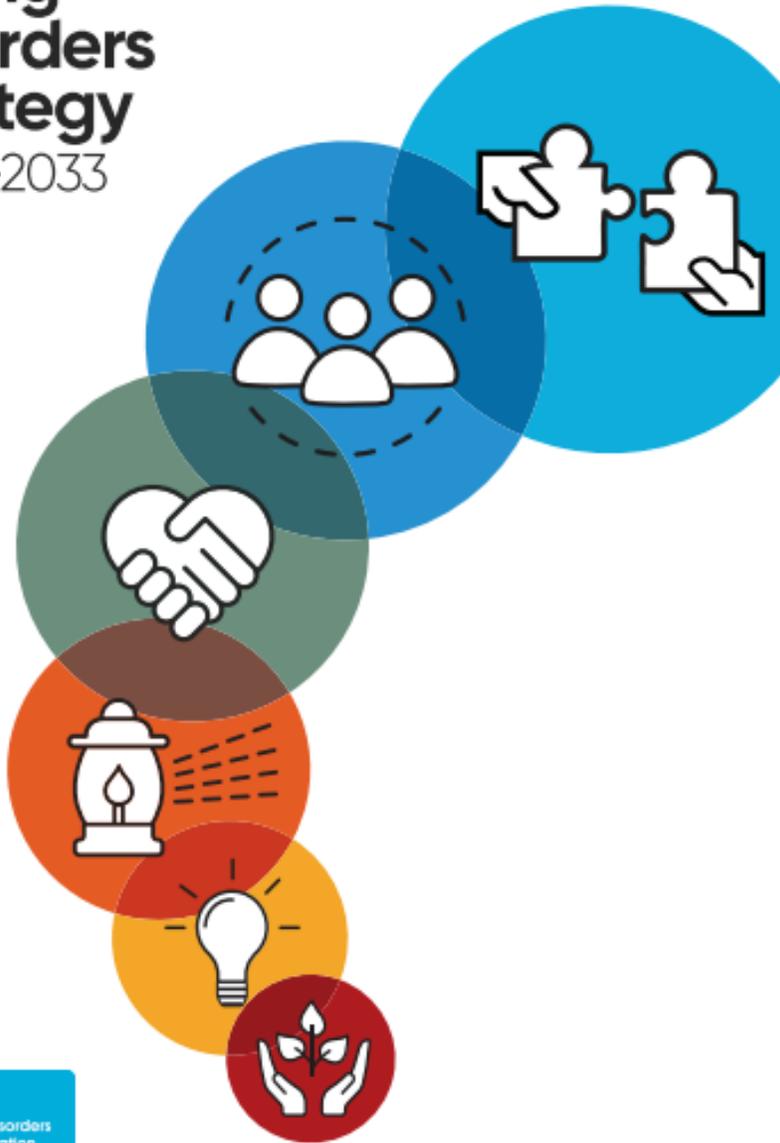- Future conversations and relationships

- Slides and summary will be provided
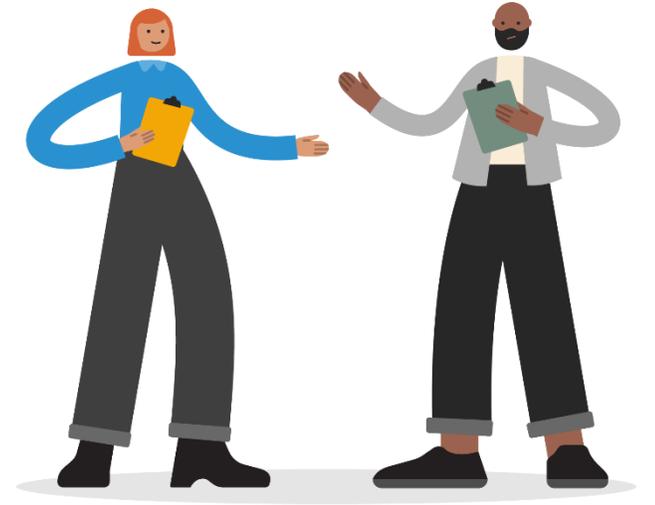
The Context

The National Eating Disorders Strategy 2023-2033

National Eating Disorders Strategy 2023–2033

- Roadmap to building the system of care

- Standards and 141 Priority Actions across the components of the system of care

- For <u>all</u> stakeholders

- We are now activating and implementing across the 141 Actions

- NEDC provides leadership, guidance, resources, and evaluation

To achieve an effective, equitable and coordinated system of care that meets the needs of people experiencing or at risk of eating disorders and their families, supports and communities.

Stepped System of Care

Principles; Guidelines; Lived experience; Research and evaluation

Involvement of person, family/supports and community

Prevention

Actions, programs, or policies that aim to reduce modifiable risk factors for eating disorders, and/or bolster protective factors, to reduce the likelihood that a person will experience an eating disorder. Eating disorder prevention actions, programs or policies may also seek to address the broader factors which impact on health, known as the social determinants of health.

Contexts: Whole of community response including: government; public health; schools and education settings; health and community services including primary care; sports, cultural, youth and other settings; lived experience organisations; media and social media; individuals, families, and communities.

Identification

Identification of warning signs or symptoms, and engagement with the person who may be experiencing an eating disorder, to support access to an initial response. In some instances, warning signs or symptoms may be self-identified, and the person may seek out an initial response themselves.

Contexts: Individuals and families; community services; schools and education settings; sports, cultural, youth and other settings; lived experience organisations; helplines and digital tools; public and private health and mental health services including general practice, community health services, child and adolescent/youth and adult community mental health services, headspace, Head to Health, Aboriginal Community Controlled Health Services, emergency departments, eating disorder-specific services.

Initial Response

Completion of an initial assessment and preliminary diagnosis, and referral to the most appropriate treatment options based on the person's psychological, physical, nutritional, and psychosocial needs. This may include facilitating access to an appropriate intervention for a person experiencing sub-threshold eating/body image concerns. An initial response should also provide psychoeducation, support the person to engage with treatment, and encourage the involvement of the person's family/supports and community.

Contexts: Public and private health and mental health services including general practice, child and adolescent/youth and adult community mental health services, headspace, Head to Health, Aboriginal Community Controlled Health Services, emergency departments, eating disorder-specific services.

Treatment

Community-based Treatment

Evidence-based mental health treatment delivered in the community, ranging from self-help and brief interventions to longer courses of treatment, in conjunction with medical monitoring and treatment, nutritional intervention, and coordinated access to a range of services and transition support as needed.

Contexts: Digital interventions; public and private health and mental health services including general practice, child and adolescent/youth and adult community mental health services, headspace, Head to Health, Aboriginal Community Controlled Health Services, eating disorder-specific services.

Community-based Intensive Treatment

Evidence-based mental health treatment delivered in the community, at a higher level of frequency or intensity than community-based treatment, in conjunction with medical monitoring and treatment, nutritional intervention, and coordinated access to a range of services and transition support as needed. Community-based intensive treatment can be delivered in a number of forms, including day programs, intensive outpatient programs, and community or home outreach interventions.

Contexts: Public and private eating disorder-specific services; child and adolescent/youth and adult community mental health services.

Hospital and Residential Treatment

Admission to hospital for people who are at medical and/or psychiatric risk, or admission to a hospital or residential program for people who are medically stable but would benefit from a higher level of treatment and support than can be provided through community-based or community-based intensive treatment options. Hospital or residential treatment should also include coordinated access to a range of services and transition support as needed. Nutritional support and intervention are a key part of hospital and residential treatment.

Contexts: Medical and psychiatric inpatient units; eating disorder-specific inpatient units; emergency departments; hospital in the home; rehabilitation units; residential eating disorder services.

Psychosocial and Recovery Support

Psychosocial support refers to services and programs which support the broader psychological and social needs of the person experiencing or at risk of an eating disorder and their family/supports and community. Recovery support refers to services and programs which support a person experiencing an eating disorder to engage with or sustain recovery or improved quality of life and assist family/supports and community in their caring role. People experiencing eating disorders and their families/supports and communities may engage in a range of psychosocial and recovery support services and programs across the system of care, at different stages of their journey.

Contexts: Community and social services; health and mental health services including primary care, headspace, Head to Health; lived experience organisations; peer support services; helplines and digital resources.

Relevant National Strategy Standards & Actions

Standard 1

People can access timely treatment and at the level of intensity they need, as close to home as possible (including digital options), and move between levels of treatment intensity in a seamless and supported way.

1.2 National, state/territory, and regional planners to ensure adequate access to treatment services in every region (including rural and remote) and for each age group (children and adolescents, transition age groups (16-25), adults, and older adults).

1.3 Treatment services within a local region (both public and private) to collaborate on service entry criteria to ensure a seamless system of care with coverage for all presentations

1.4 All treatment services to support people and their families/supports to transition between services and levels of treatment (step-up, step-down, and within level) through clear inter-service communication and tailored care navigation

1.5 Treatment services to allocate dedicated staff time for supporting connection with other services and clinicians, and maintaining up-to date knowledge of the local service system

Relevant National Strategy Standards & Actions

Treatment – Hospital and residential

Standard 1
There is sufficient access to hospital beds and residential care to meet the medical and psychiatric needs of children and adolescents, transition age groups (16-25), adults, and older adults.
1.1 State and territory governments to map the need for inpatient care for people across age groups and provide greater access to beds as required

The Context

What is happening for a young person during 16-25yo?

What is happening for a young person?

= major life transitions

Approaching or reached adulthood 18+	Major life decisions	Leaving school	Commencing further education
Commencing work	Shift in financial dependence / independence	Moving out of home	Moving away from family and friends
Personal identity	Ability to legally make decisions for self	Independence (e.g. driving)	Changes in friendships and relationships
Physical changes	Life pressures and stressors (ed, work, $)	Medicare	Family payments

Prevention

Identification

Response

Family and supports

Health professionals

Treatment

Psychosocial and Recovery Support

National Eating Disorders Collaboration

Where are the gaps in service provision?

- Evidence-based approaches: what model and when do we change?
  - FBT to CBT, etc
- Inclusion of families
- Transition care between services
- Determination of care for the 16-18yo: who can access treatment?
- When does transition happen? (e.g. rigid 18th birthday or flexible)
- Care provision within each service type (e.g. treatment v case management)
- Eligibility:
  - CAMHS to AMHS
  - Outpatient to inpatient
  - Hospital care: dedicated ED, medical, psychiatric
  - Community-intensive programs

The Context

What does the literature say?

Documented transition barriers

Inadequate preparation for adult care

(Dimitropoulos et al., 2013; Lockertsen et al., 2020a; Nadarajah et al., 2021)

Inconsistent and poorly-timed transition planning

(Dimitropoulos et al., 2015; Nadarajah et al., 2021)

Lack of individualised care

(E.g., developmental age vs chronological age, maturity fears, low self-esteem)

Lack of access to adult services

(Dimitropoulos et al., 2015)

Parents unsure of their role and dearth of support

(Lockertsen et al., 2021)

What are the consequences of transition disruptions?

Interruptions in care leave adolescents feeling anxious, lonely, and stressed

(Dimitropoulos et al., 2013; Nadarajah et al., 2021)

Some young people resume eating disorders behaviours

(Lockertsen et al., 2020a)

Increased risk of relapse post-transition

(Dimitropoulos et al., 2015; Lockertsen et al., 2021)

Parents report feeling lost, distressed, and powerless

(Lockertsen et al., 2021; Nadarajah et al., 2021)

Adolescents disengage from services

(Dimitropoulos et al., 2013; Lockertsen et al., 2020b)

ed

Sharing the Challenge

Examples of service challenges

|				
Chronological vs developmental	Complexity of age period	High rates of dropout prior to transition	Differences in Treatment b/w C & A	Involvement of family
Inconsistent eligibility between C & A	When does transition happen?	Inconsistencies between services/Different systems	Different departmental age cut offs within one health service	Differences in community services
Transition aged people accessing services for the first time	Adult services not accepting ED clients	Age criteria mismatch for bedlinks in metro services	Location of medical monitoring – In CAMHS but not in AMHS	Transfer of responsibility
	Difference in philosophy around medical admissions	Differences in rigid/flexible boundaries around age transitions	Lack of follow up post-transition	Varying levels of family support available
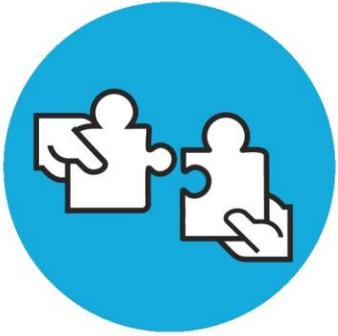
Your identified service challenges

Funding/lack of funding

Recognition of need for treatment – adult services

Systems pressures

All services operating differently (inconsistency between eligibility criteria between services, differences in age criteria's between services)

Lack of understanding between services as to what they offer (CAMHS not sure what AMHS offer and vice versa)

Limitation capacity and capability

Chronical vs. developmental. Different departmental age cut offs

Difficulties preparing young people for transitions (adult services not equipped to treat young people) and therefore difficulties managing expectations around transitions.

Family involvement

Finding the solution

Transition interventions

Transition passport

(Nadarajah et al., 2021)

Navigation Guide

(Dimitropoulos et al., 2013, 2015; Singh et al., 2010)

Early transition planning

(Gray et al., 2018; Nadarajah et al., 2021)

Parental Involvement

(Dimitropoulos et al., 2013; Nadarajah et al., 2021)

A pre-transition meeting

(Colver et al., 2020; Dimitropoulos et al., 2015)

Assessing readiness to transition

(Nicula et al., 2023)

Service Level Transition Interventions

Amending age range of services

(CAMHS extending to 25 years and AMHS continue treating young adults (16/18–25s)

Greater service alignment between CAMHS and AMHS

(e.g., Using common language across services, similar thresholds for admission)

Transition Coordinator

(Annunziato et al., 2013)

Feasibility and Acceptability of a Transition Intervention for Young People with Eating Disorders

Nicula et al. (2023) recruited nine adolescent-parent pairs for their transition intervention designed to support adolescents and parents in the transition from paediatric to adult mental health services.

Intervention (completion rate %)

- Youth-to-Youth session (90%)
- Parent-to-Parent session (100%)
- Transition Meeting (100%)
- Family doctor contact (40%)
- Navigation Guide (60%)

Change in adolescent outcomes

No significant differences in self-reported ED symptomology, transition readiness and self-management skills were found from baseline to post-intervention among the adolescent sample (N = 6).

All adolescents reported the intervention as helpful and informative. Peer sessions and family doctor contact were endorsed as the most helpful interventions.

Change in parent outcomes

Most dimensions of caregiver burden, except guilt, did not change after the intervention.

Finding the Solution

Solution summary

|			
Early transition planning: 6-12 months	Inter-team collaboration – Tailoring approach to needs of YP	Consistent parental involvement	Navigation/transition guide
Amending age eligibility of services	Service alignment (child to adult)	Transition coordinator/Identified role	Transitional peer support
Identifying champions to advocate for system change & engage with Ministers	Local workshops to explore the transitional needs of a region/state	Aligning with relevant standards and government documents	National standards for transitional care pathways
Service mapping – what is available and who is eligible?	Identify barriers and facilitators of effective transition from your service	Using frameworks from other chronic health and chronic conditions	Role of GP in scaffolding transition time
Offer varying levels of transition support depending on acuity/risk/presentation	IT integrations for information sharing/Data transfer	Family inclusion framework to support staff not confident in family work	Workforce development offerings to assist in transitions

Next steps

- Evaluation survey

  - Did this format work?

  - What else do you need to overcome these identified service challenges?

  - Are there other service challenges that you need support with?

- Connecting with others in the meeting

- Summary of the literature and notes from today

- Other suggestions or comments?
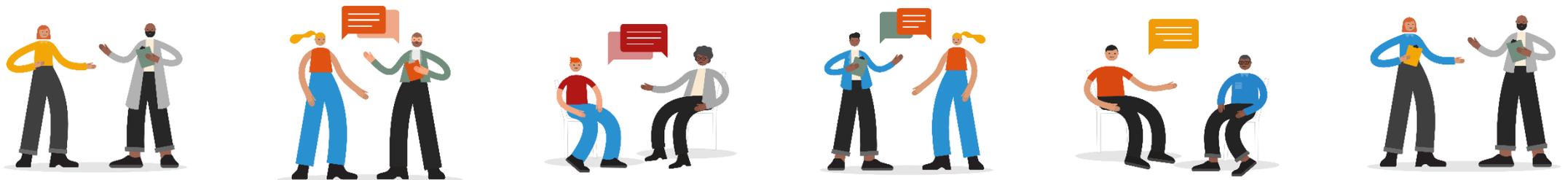
www.nedc.com.au   nationalstrategy@nedc.com.au

References

Annunziato, R. A., Baisley, M. C., Arrato, N., Barton, C., Henderling, F., Arnon, R., & Kerkar, N. (2013). Strangers headed to a strange land? A pilot study of using a transition coordinator to improve transfer from pediatric to adult services. The Journal of pediatrics, 163(6), 1628–1633. https://doi.org/10.1016/j.jpeds.2013.07.031

CanChild. *MyTransition App*. Available online at: https://www.canchild.ca/en/research-in-practice/current-studies/apply-the-mytransition-app-in-transition-applyit-study/mytransition-app (accessed March 1, 2025).

Colver, A., Rapley, T., Parr, J. R., McConachie, H., Dovey-Pearce, G., Couteur, A. L., McDonagh, J. E., Bennett, C., Maniatopoulos, G., Pearce, M. S., Reape, D., Chater, N., Gleeson, H., & Vale, L. (2020). Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. *Clinical Medicine*, 20(1), 74–80. https://doi.org/10.7861/clinmed.2019-0077

Dimitropoulos, G., Toulany, A., Herschman, J., Kovacs, A., Steinegger, C., Bardsley, J., Sandhu, S., Gregory, C., Colton, P., Anderson, J., & Kaufman, M. (2015). A qualitative study on the experiences of young adults with eating disorders transferring from pediatric to adult care. Eating Disorders, 23(2), 144–162. https://doi.org/10.1080/10640266.2014.976106

Dimitropoulos, G., Tran, A. F., Agarwal, P., Sheffield, B., & Woodside, B. (2013). Challenges in making the transition be-tween pediatric and adult eating disorder programs: A qualitative study from the perspective of service providers. Eating Disorders, 21(1), 1–15. https://doi.org/10.1080/10640266.2013.741964

Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from pediatric to adult care: A systematic review. *Journal of Pediatric Psychology*, 43(5), 488–502. https://doi.org/10.1093/jpepsy/jsx142

Lockertsen, V., Nilsen, L., Holm, L. A. W., Ro, O., Burger, L. M., & Rossberg, J. I. (2020a). Experiences of patients with anorexia nervosa during the transition from child and adolescent mental health services to adult mental health services. Journal of Eating Disorders, 8(1), 1–11. https://doi.org/10.1186/s40337-020-00313-4

Lockertsen, V., Nilsen, L., Holm, L. A. W., Ro, O., Burger, L. M., & Rossberg, J. I. (2020b). Mental health professionals' experiences transitioning patients with anorexia nervosa from child/adolescent to adult mental health services: A qualitative study. BMC Health Services Research, 20(1), 1–9. https://doi.org/10.1186/s12913-020-05740-2

Lockertsen, V., Holm, L. A. W., Nilsen, L., Ro, O., Burger, L. M., & Rossberg, J. I. (2021). The transition process between child and adolescent mental services and adult mental health services for patients with anorexia nervosa: A qualitative study of the parents' experiences. Journal of Eating Disorders, 9(1), 1–10. https://doi.org/10.1186/s40337-021-00404-w

Nadarajah, A., Dimitropoulos, G., Grant, C., Webb, C., & Couturier, J. (2021). Impending transition from pediatric to adult health services: A qualitative study of the experiences of adolescents with eating disorders and their caregivers. Frontiers in Psychiatry, 12, 726. https://doi.org/10.3389/fpsyt.2021.624942

Nicula, M., Kimber, M., Boylan, K., Grant, C., Laliberté, M., Miller, K., Dimitropoulos, G., Trollope, K., Webb, C., & Couturier, J. (2023). Assessing the feasibility of an intervention for adolescents and parents transitioning out of paediatric eating disorder services: A mixed methods study. *European Eating Disorders Review*, 1–18. https://doi.org/10.1002/erv.3027

Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., Hovish, K., Islam, Z., Belling, R., & White, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *The British Journal of Psychiatry*, 197(4), 305–312. https://doi.org/10.1192/bjp.bp.109.075135