

beyond the hospital walls: a patient perspective on supporting chronically ill adolescents past the acute setting

Presenter information:

Presenter 1:

Name: Stella Hemingway (she/her)

Organization: The Royal Children's Hospital

Position: Program participant & Peer Leader - ChIPS

50-word Biography / summary of expertise: Stella is a passionate advocate with lived experience of chronic illness. As a participant and peer leader in the ChIPS Program, she supports other young people navigating complex health needs. Stella also works within hospital settings, gaining insight into healthcare delivery and championing patient-centered approaches across pediatric and adult care.

Presenter 2:

Name: Inga Pieniazek (they/them)

Organization: The Royal Children's Hospital

Position: Program participant - ChIPS

50-word Biography / summary of expertise: Inga has a bachelor's in applied science (Psychology), and works as a Education Coach for Primary School students. Inga has been living with chronic illnesses and disability since early childhood. She aspires to combine education, psychology, and art into her community to advocate for children's and young people's future.

Presenter 3:

Name: Charlie Kennedy (she/her)

Organization: The Royal Children's Hospital

Position: Program participant - ChIPS

50-word Biography / summary of expertise: Charlie is currently pursuing her bachelor's in social work at university while also having lived experience of disability and associated chronic illness. She uses these experiences to influence her work within the youth advocacy sector, specifically focussing on education and mental health and their intersections with disability and chronic illness.

Presenter 4:

Name: Mac Zamani (he/him)

Organization: The Royal Children's Hospital

Position: Program participant & Peer Leader - ChIPS

50-word Biography / summary of expertise: Mac's a proud queer, disabled CALD youth advocate. He is a public speaker, writer, consultant and facilitator, who has lived experience of chronic illness and disability. He's a multi-award-winning advocate (takeover Melbourne award winner, 30 under 30 award replicant, disability leadership award finalist) who is passionate about creating system change.

Background/ Overview of Workshop:

Developed and delivered by young people with lived experience of chronic illness, this workshop explores how health professionals can better support adolescents and young adults beyond the acute hospital setting.

Chronic illness affects approximately 7% of all adolescents in Australia, yet only 1% qualify for the National Disability Insurance Scheme (NDIS). This leaves the majority navigating fragmented systems without coordinated, long-term care. Existing assessment tools often fail to capture the holistic picture of a young person's life—focusing narrowly on clinical need and overlooking mental health, education, and social participation.

Drawing on lived experience and real-world examples, presenters will highlight the challenges faced when transitioning from paediatric to adult healthcare, including the sudden loss of allied health and multidisciplinary support. Participants will engage in case-based discussions to identify service gaps, explore advocacy strategies, and consider practical, youth-informed approaches to improving continuity of care and long-term outcomes.

Target Audience:

Please select from the following:

- Community / youth workers
- Health professionals

Learning Objectives:

By the end of this session, participants will be able to:

1. *Recognise the systemic barriers facing adolescents with chronic illness, particularly those ineligible for the NDIS.*
2. *Understand the lived experience perspective on navigating fragmented healthcare systems.*
3. *Identify services accessible during and after transition to adult care and the limitations within them.*
4. *Apply a youth-informed, advocacy-based approach to supporting patients beyond hospital walls.*

Duration of workshop:

- 60 minutes

Will this workshop be co-presented with young people?

- Yes

Disclosure of Interest Statement:

The Royal Children's Hospital is committed to upholding the highest standards of professionalism and integrity in healthcare practice. There are no conflicts of interest to report from the development of this training or the abstract material.