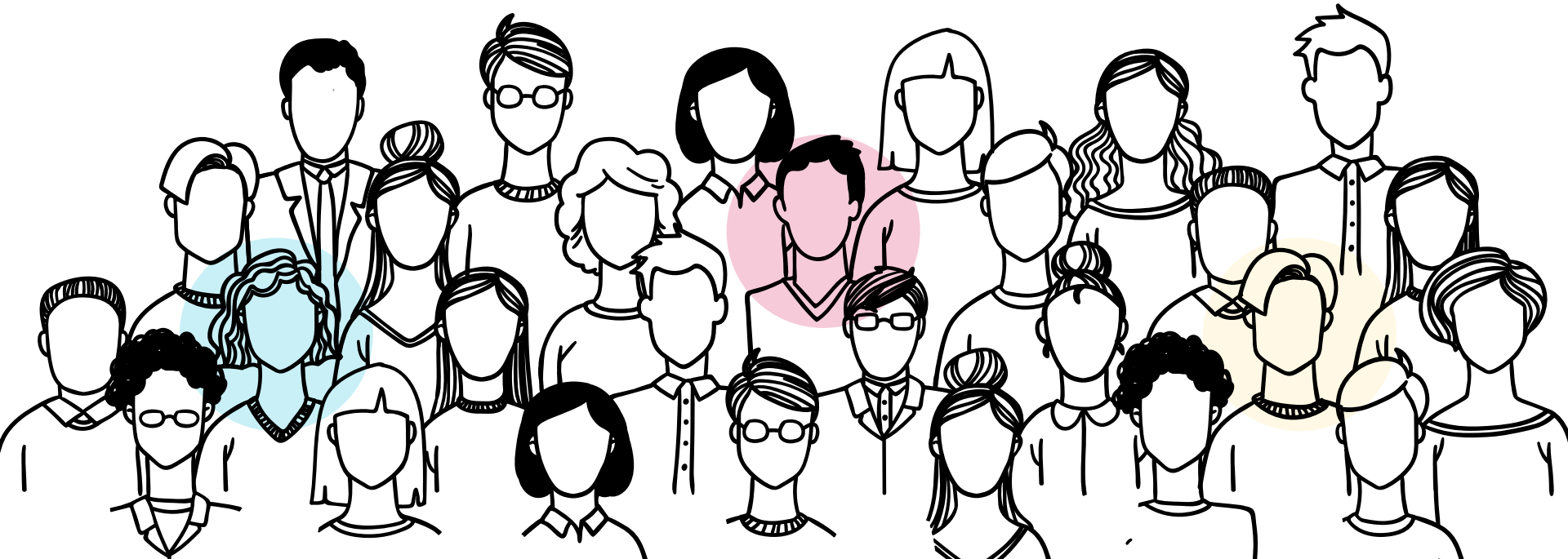
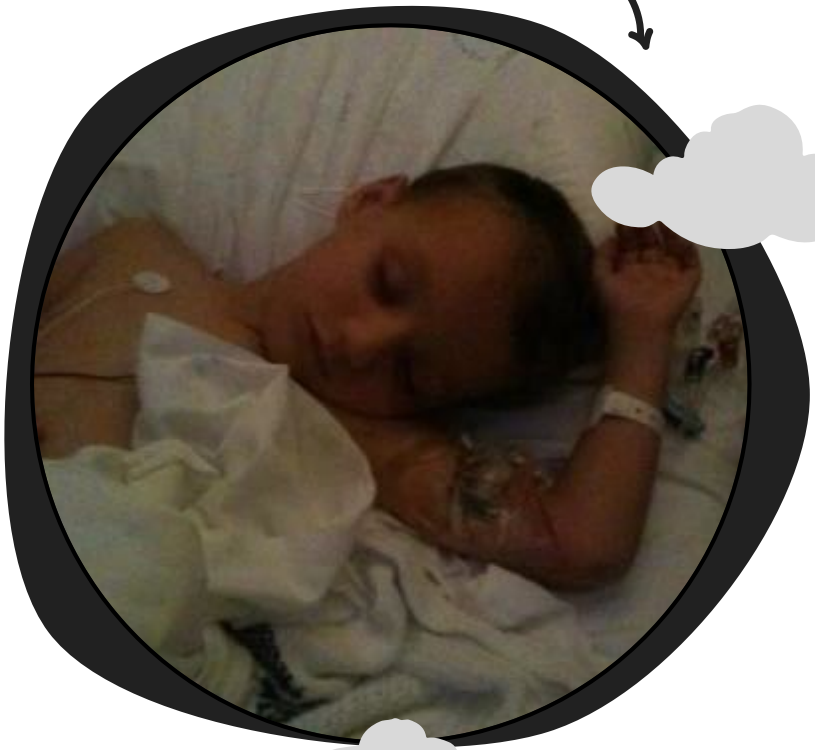
Transition of Health Services

PAEDIATRIC TO ADULT IN THE CONTEXT OF
COMPLEX DISABILITY & HEALTH CONDITIONS

A family perspective





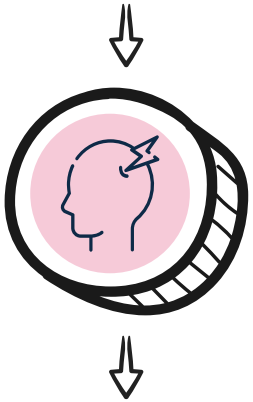
The beginning - Harry’s battle with Meningoencephalitis and a rare genetic mutation

A Future Changed…. Brain Injury, rare disease & genetics

ACQUIRED BRAIN INJURY

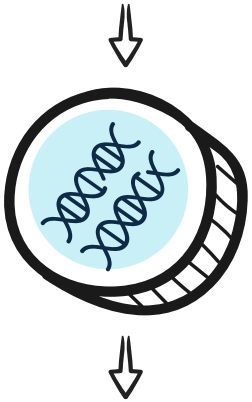
Loss of function and reduced capacity in learning and IADLs

AUTOIMMUNE ENCEPHALITIS



Ongoing medical Intervention with increasing trauma

RARE GENETIC CONDITION

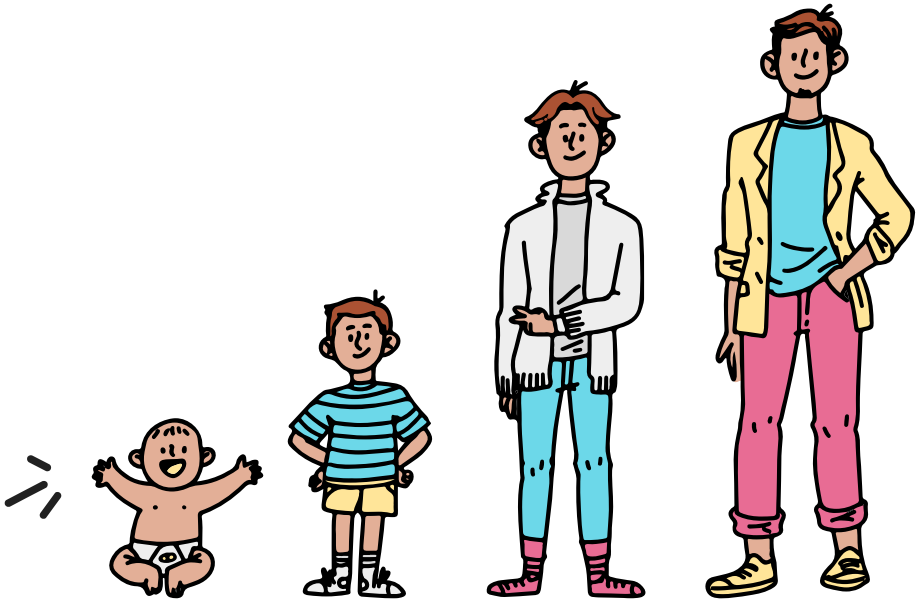


Neuro-developmental disability & a dysfunctional immune system

The now - Living with complex disability and health conditions

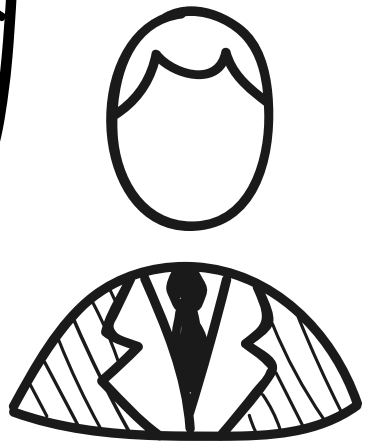
LIFE STAGE TRANSITION

Adolescence to Young Adult

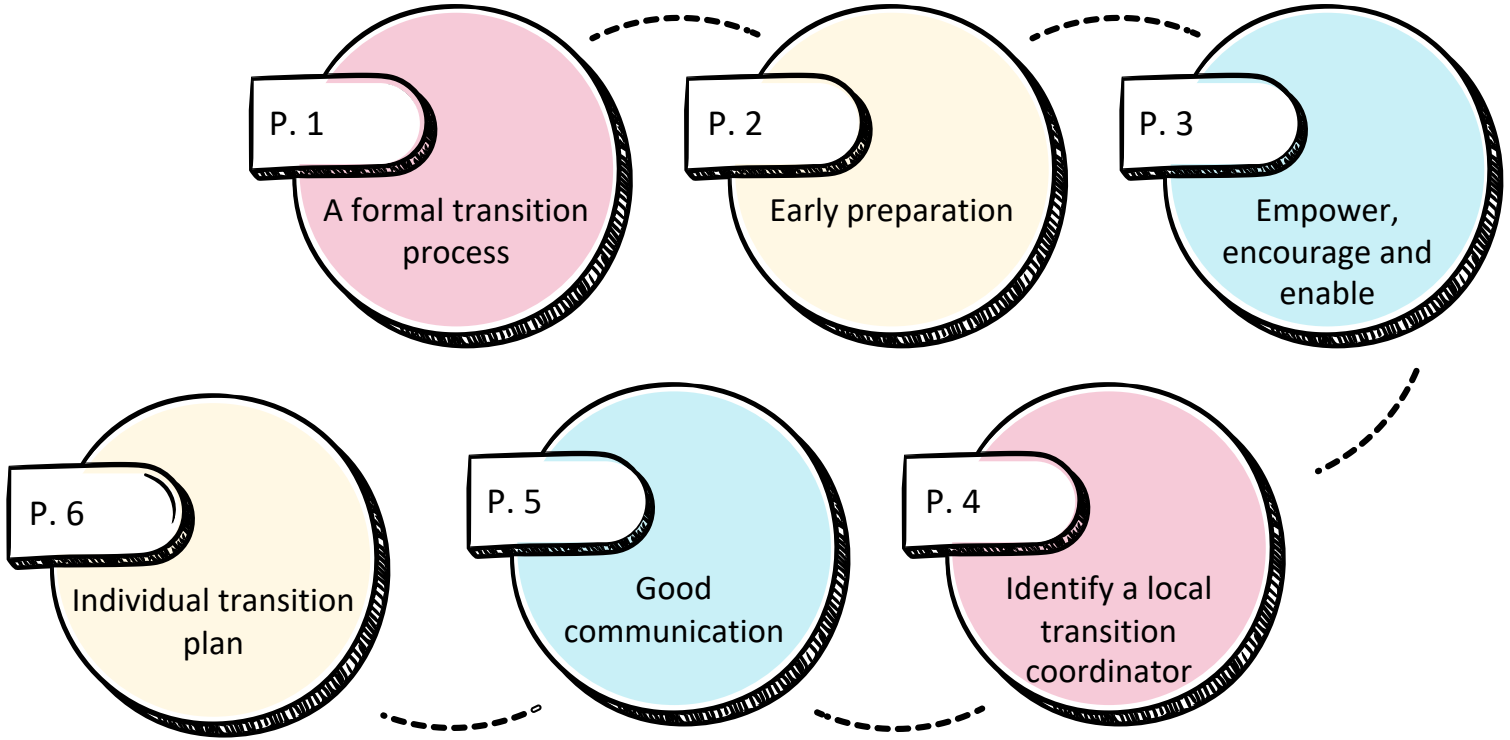


- Developmental
- Education
- Government system transfer:
  - Medicare
  - Centrelink
- NDIS
- Healthcare

Transition - “a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child centred to adult-oriented health care systems" (Society of Adolescent Medicine 2003).



KEY PRINCIPLES FOR TRANSITION CARE



Transitioning in the context of intellectual disability from a family perspective

Barriers!!

- Loss of extensive knowledge and trusted relationships
- Communication
- Transfer of medical files/support plans
- Accessibility – (environment, family/caregivers, sensory)
- Increased risk of adverse outcomes for those not appropriately supported
- Interdisciplinary to multidisciplinary care model
- State wide service to LHD model – challenges accessing health professionals

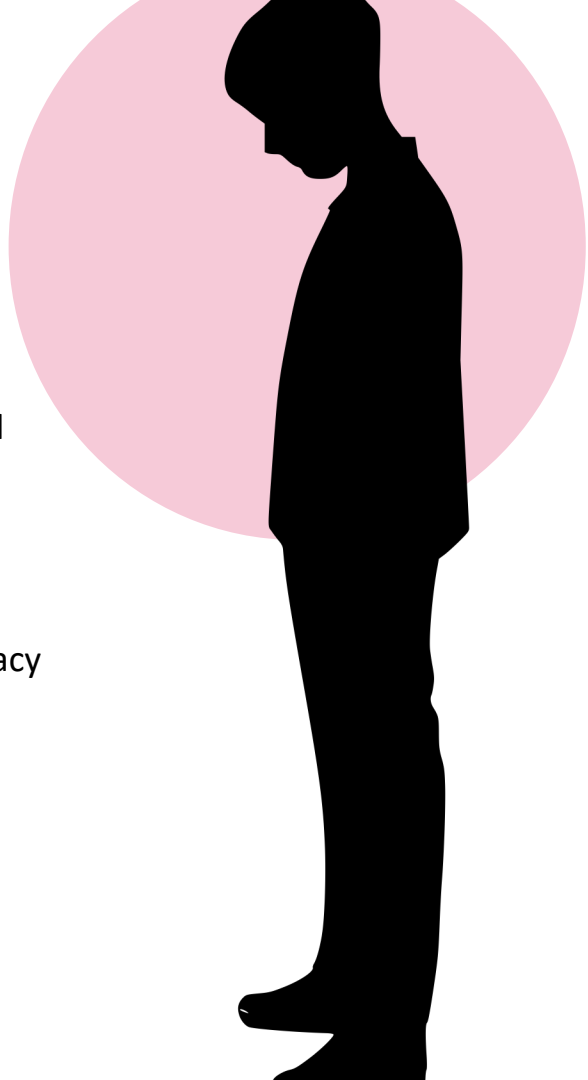
Benefits!!

- Person centred care
- Building of independence
- Reduced travel
- Access to new treatments not available in a paediatric setting
- More ‘appropriate’ environment/setting for a young adult

IN REAL TERMS…

My family's experience
commencing transition process.

- Disability and complex behaviours impacting quality and access to healthcare
- Current transition process is based on the patient being able to communicate their needs and wants
- Poor communication with stakeholders, including accuracy of medical information be shared
- Limited partnership in care with primary caregivers
- An interagency model of care is not promoted, despite significant disability related support needs



Transition care consumer experiences report – ACI 2023

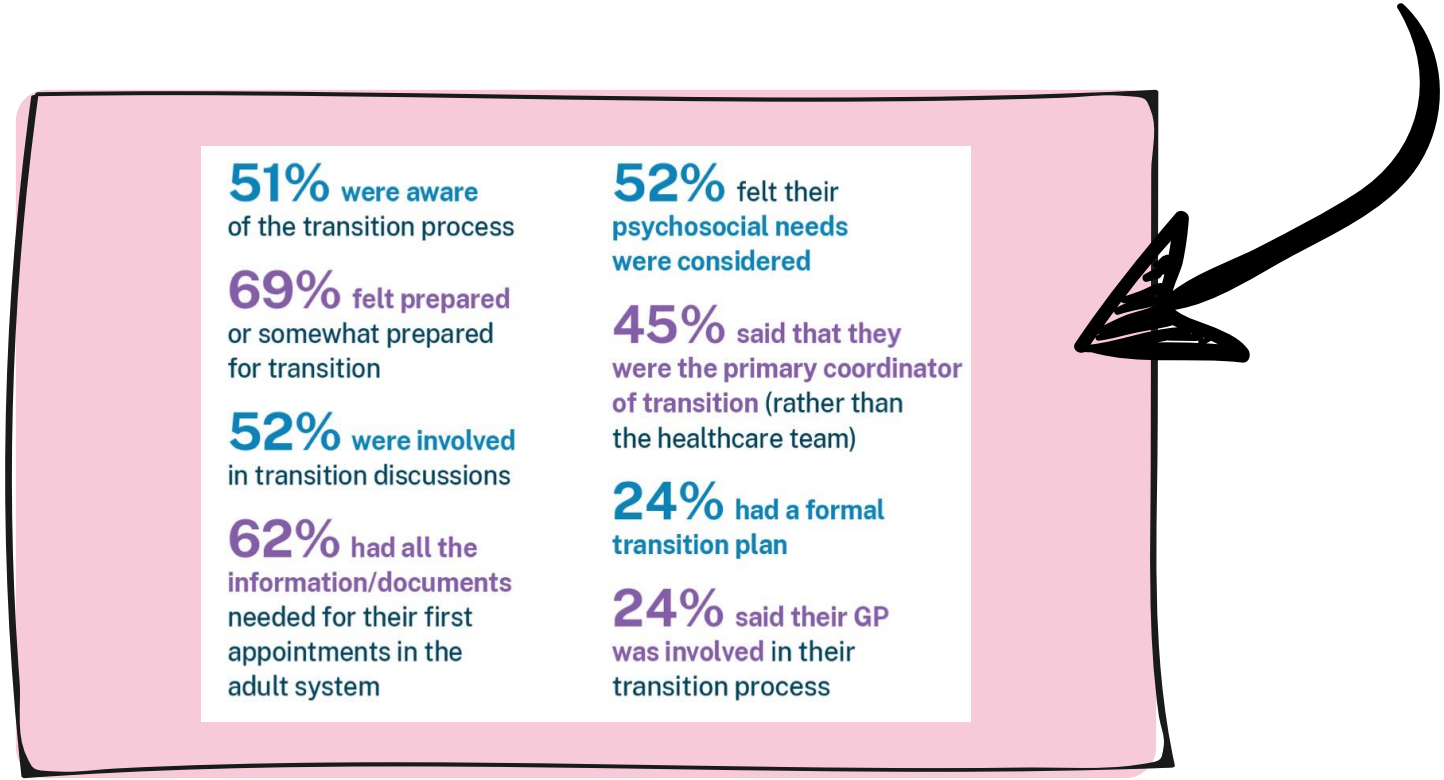
Early Preparation

”We haven’t received any information or letters about transitioning and are worried there will be a big gap in the medical needs of my child.”

Individual Transition Plan

”It is hard to find a team that will take on my complex issues.”

TRANSITION EXPERIENCES BREAKDOWN – ACI 2023



TRANSITION MY WAY

Developing an authentic, person-centred model

Within an interagency approach.

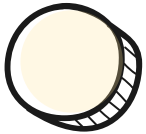

Bring stakeholders to the table for planning

Stakeholders in Transition – Intellectual Disability

YOUNG PERSON

FAMILY/CAREGIVERS

ALLIED HEALTH TEAM



TRANSITION COORDINATORS

Trapeze/ACI

NDIS

MEDICAL TEAMS

Paediatric/Adult inclusive of GP

UNDERSTANDING HARRY'S CHALLENGES IN ACCESSING HEALTHCARE AS A YOUNG PERSON WITH A COMPLEX DISABILITY SEEKING QUALITY OF LIFE!!

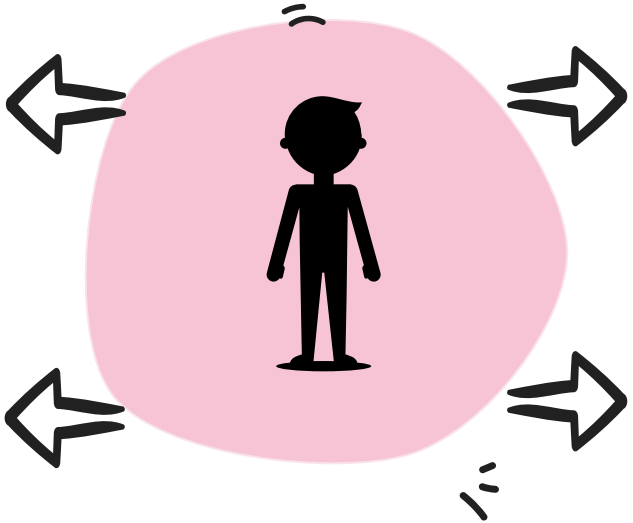
MAPPING OUR TRANSITION PATHWAY

ACCESS TO HOSPITAL FOR TREATMENT / EMERGENCY

Identification of medical supports required
CNC Oversight
Management Plans

MANAGING THE ENVIRONMENT

Is the hospital environment suitable?
Does this treatment need to occur in hospital, if not where?



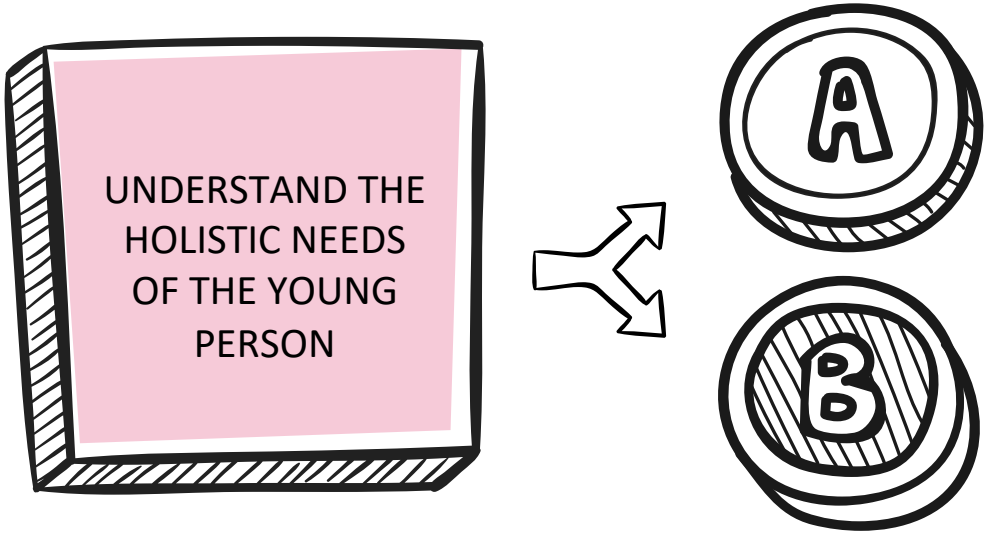
BASELINE INFORMATION / DIAGNOSTICS

Ensuring all medical and social history is correct for transition

CASE REVIEW/PATHWAY DEVELOPMENT

Collaboration with all stakeholders to assess, review and strategise

UNDERSTANDING THE BARRIERS – MAKING WAY FOR INNOVATION IN HEALTHCARE DELIVERY



HOME BASED TREATMENTS

Reduction in chemical restraint, reduced medical trauma and improved quality of life etc.

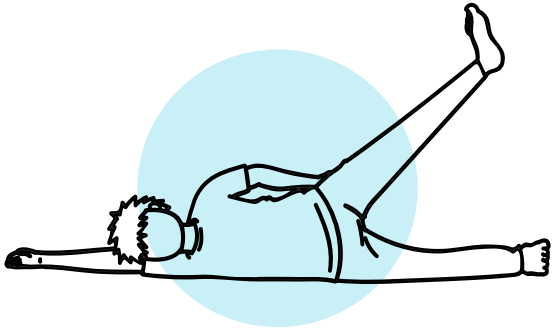
HOSPITAL BASED SUPPORTS

Access issues for regular inpatient treatment, bed availability, increased trauma, resource heavy, required in emergencies

WHAT CAN BE ACHIEVED THROUGH COLLABORATION?

- Model of best practice which is least restrictive in its implementation
- Insight into sensory needs
- Development of a communication profile
- Inclusion of behaviour support and training of staff
- Reduction in incidents
- Improved safety for all stakeholders
- Improved access to healthcare
- Dignity in the provision of healthcare supports

Thanks for your time and support!



Questions?