Government of **Western Australia**
Child and Adolescent Health Service

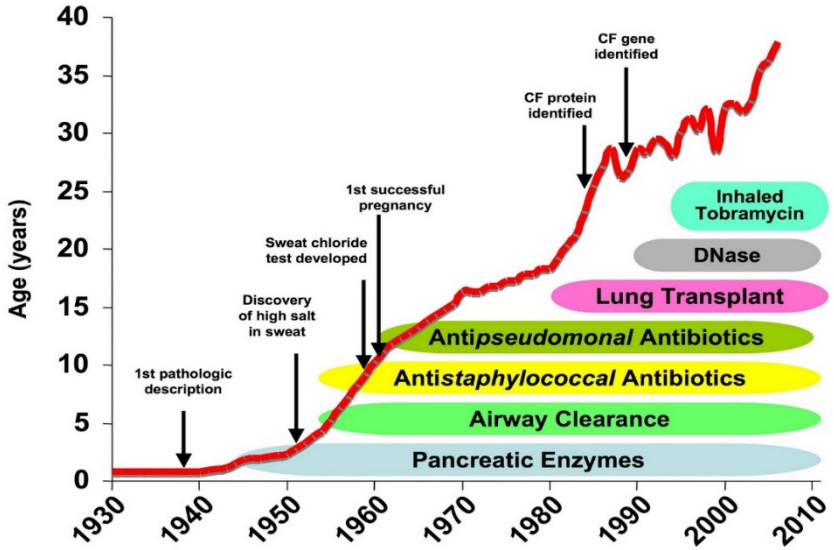
TRANSITION

Clinical Senate
April 2019

Child and Adolescent Health Service

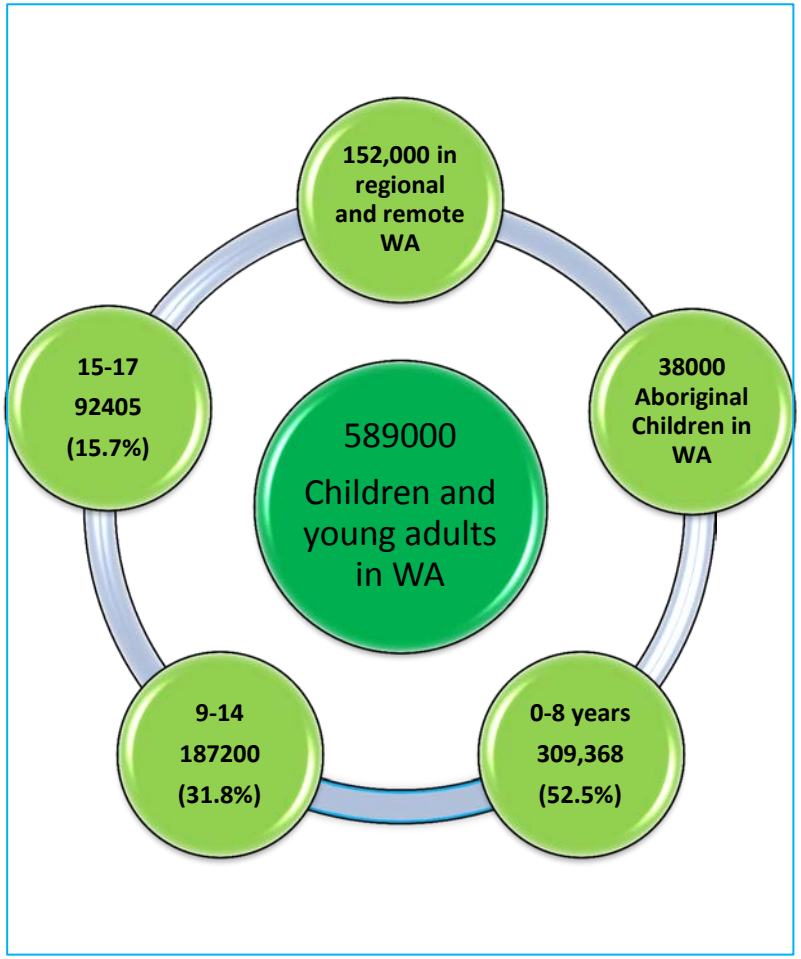
"the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult health-care systems"

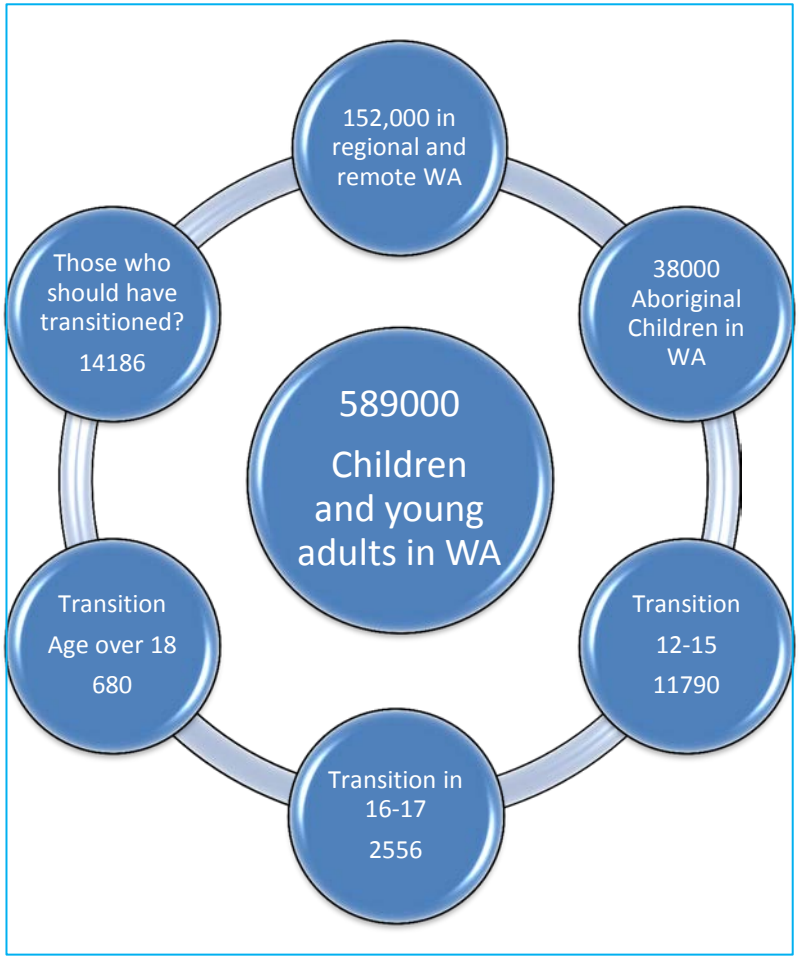
Type 2 Diabetes has risen from 5% to 1:5



- By 2013, mortality in 1 to 4 year olds had fallen to around a quarter of 1980 levels
- By contrast, deaths in 20 to 24 year olds had only fallen to around 60% of 1980 levels.
- Deaths in many high-income and middle-income countries are now higher in older male adolescents than in 1 to 4 year olds.

So what does our data look like?





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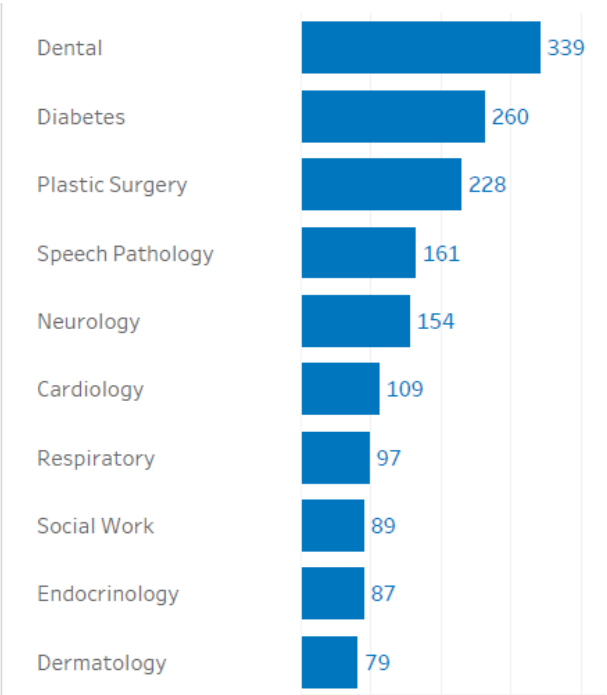

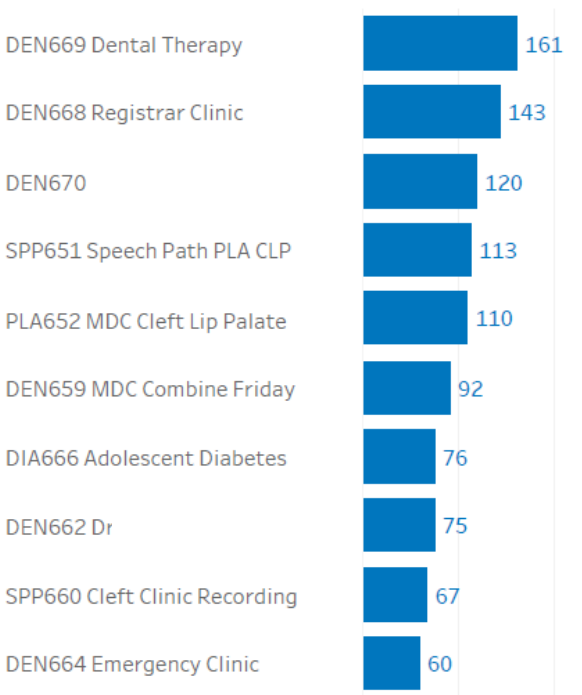

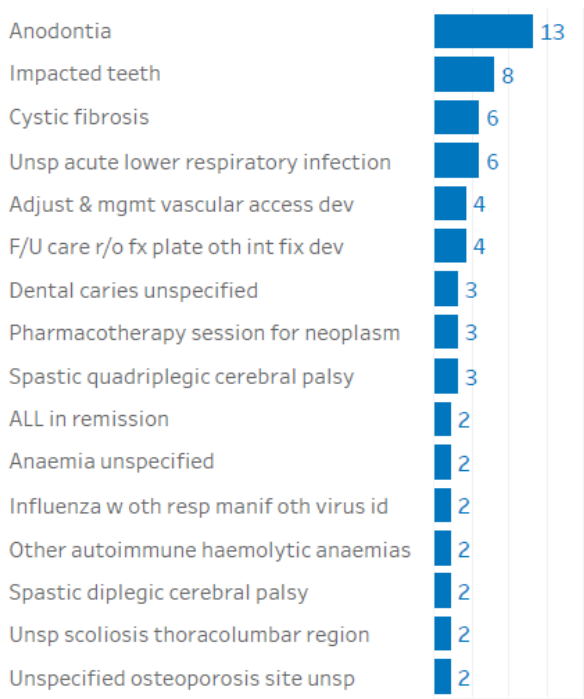

Priority 2.3: Young people with complex and ongoing health and wellbeing needs are supported to optimise transition from paediatric to adult care

The WA health system recognises the importance of transition, as indicated by the inclusion of 'transition' as a priority area in the most recent *WA Health Clinical Services Framework (2014–2024)*.[18]

The term, 'transition' is used to describe the process of planning, preparing and moving from a paediatric health care service to an adult health care service.[19] There is increasing evidence that over this period young people are particularly at risk of[20]:

- suboptimal medical follow up
- reduced treatment adherence
- increased service costs resulting in poorer health outcomes.

> *(There is a need for) information and support around transition. Can be socially isolating, especially with a disability that isn't well understood.*

Communication processes and tools are central to supporting person-centred care for the young person as they transition to adult services. Key styles of communication that will build a young person's confidence to self-manage their health include[21]:

- openness
- transparency
- collaboration and a willingness to work together.

Transition is a process and should encompass a holistic and collaborative approach that is supported by both adult and paediatric services.

The principles for successful transition and transfer have been outlined in the *Paediatric Chronic Diseases Transition Framework (2009)*.[20] These principles include:

- **Planned and coordinated care** – Planning should begin in early adolescence. It should involve coordination between health services throughout and should be clear to the young person, their families, carers and health professionals. The process, responsibilities and steps involved should be clearly defined.
- **Readiness for transition** – This will occur at different times and pace for all young people. Young people need to be equipped with appropriate and adequate knowledge to self-manage their condition, allowing them to flourish in adult life.
- **Ownership of transition by the young adult when possible** – A young person needs preparation and support to take ownership and responsibility for their health condition and care requirements to progress safely to autonomy.
- **Shared responsibility by all involved in the transition** – Partnerships between paediatric and adult specialist health services, primary health carers, school and community health care professionals, patients and their families or carer are needed to ensure a collaborative and consistent approach to transition. GPs and other primary health professionals need to be consistently included in the planning and implementation of transition plans.
- **Accessibility and availability of appropriate services** – Youth friendly services are required in all health settings. Specialist liaison and intervention services need to be identified and strengthened for vulnerable youth populations.

Health services can directly support young people to transition from paediatric to adult care by:

- implementing the strategies laid out in the *Paediatric Chronic Diseases Transition Framework (2009)*[20]
- recognising that transition is a continuous process
- clearly identifying who is/are responsible for transition coordination responsibilities
- developing and implementing individual transition plans that:
  - consider developmental needs and vulnerabilities
  - encompass a holistic and collaborative approach
  - are developed in partnership with the young person, their family or carer
  - are available to and understood by the young person, their family or carer and all relevant health professionals and services
  - provide opportunity for regular feedback from the young person, their family or carer which informs updates to the plan
- evaluating transition programs to inform service planning
- establishing a state-wide transition coordination network for coordinators to collaborate and share learnings.

Priority Area 2.3: Young people with complex and ongoing health and wellbeing needs are supported to optimise transition from paediatric to adult care

No.	Outcomes required to achieve this priority
2.3.1	Health Service Providers develop an agreed systematic and formal transition process for all young people living with complex and ongoing health and wellbeing needs, starting in early adolescence
2.3.2	Agreed standardisation of transition ages across health services
2.3.3	Health services working with young people living with complex and ongoing health and wellbeing needs commit to the development and implementation of transition programs
2.3.4	Health Service Providers assign transition coordination responsibilities to a position based in a paediatric and an adult health service
2.3.5	All young people and their families or carer are aware of the assigned health professional responsible for supporting their transition
2.3.6	A transition readiness checklist is completed at regular intervals from early adolescence
2.3.7	Health services provide resources covering transition and associated services available to young people and their families or carer
2.3.8	Health Service Providers monitor and evaluate transition processes to inform future planning, policy and services
2.3.9	Young people living with complex and ongoing health and wellbeing needs are supported to develop skills to manage their health as early as possible to aid transition

- There is plenty of guidance on what makes for good transition planning and good commissioning of care
- a significant shortfall between policy and practice
- For young people, their families – and sometimes the staff caring for them – this creates confusion and frustration.
- Even worse, young people can find themselves without essential care or equipment because of the different ways services are provided, or while funding arrangements are resolved.
- There is good evidence that ***morbidity and mortality*** increase for young persons following the move from paediatric to adult services

chronic, complex, disabling and require frequent, specialist care throughout the life span. This necessitates access to multiple doctors, allied health workers, pathology and pharmacy services.

have been engaged in a paediatric, family- centred multidisciplinary model of care. They need preparation and support to move into adult services, which are more specialised, less integrated, and centred more on the individual than on the family.

Failed transition leads to poor engagement with health services and adverse health outcomes.[2]

Should we be changing our pre-conceptions such that paediatricians should look after older kids ie *adults*

timing of transition according to developmental stage and maturity, **not age**

Should we ask Geriatricians to look after younger patients?

- receiving clinician according to complexity

So what is our ask today ?

- Learn from existing exemplars of transition
- Generosity to share knowledge
- Acknowledge, respect and build on the considerable body of work and partnerships in this space in WA
- Most importantly - DO so that is more than a talking shop!

Thank you

Regardless of which chronic and complex disease they have, **these young people face similar problems with the transition to adult care**:

- inadequate preparation
- difficulty finding appropriate adult health services
- inadequately coordinated specialist adult services
- unwillingness of general practitioners to take on complex cases
- inadequate resources to coordinate the transition process
- lack of psychological support.

comprehensive preparation for transition, involving the family and adult services

- timing of transition according to developmental stage and maturity, **not age**
- flexibility from adult specialists to allow parents and carers to attend some consultations
- clinics that treat many different rare chronic conditions
- GP clinics that are competent and confident to coordinate care and refer appropriately