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# ***Transition to Adult Care: an Australian Perspective***

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## ***Why do we need specialised centres?***

- ◆ MPS and related disorders are rare conditions
  - expertise can only be gained by experience/time and exposure
- ◆ Specialised centers can provide
  - knowledge of the natural history of the disorder
  - experience in identifying and monitoring disease complications
  - team health professionals eg.OT,physio,social worker etc
  - facilitate and coordinate access to variety of sub specialists (eg cardiologists, ophthalmologists, neurosurgeons, orthopaedics, ENT, palliative care etc.)
  - co-ordinate holistic care of individual
- ◆ Can facilitate contact and connection of individuals and families
- ◆ Provide access to/information on emerging new/novel therapies

## ***Why do we need specialised centres?***

- ◆ Ideally clinic would be “one stop” shop
  - Individualised
  - Co-ordinated
  - Integrated
  - Multidisciplinary
  
- ◆ Even within paediatric setting this is often difficult to achieve.

## ***What has been happening when an individual reaches adolescents/adulthood?***

- ◆ Because such services are established in the paediatric setting for a long time adults who have childhood onset, chronic, complex disorders have tended to stay on in the paediatric services for their care.
- ◆ Really only in the past decade the inappropriateness of this and the importance of transition to an adult setting is increasingly being recognised.



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## ***What is “transition” ?***

“the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from a child-centred to adult –oriented health care systems”- American Society of Adolescent Medicine.

## ***Why do we need to transition to an adult service?***

- ◆ Individuals with chronic diseases are surviving longer with 'medical advances'/improved medical care.
- ◆ Adults have specific medical needs that will not be met in paediatric setting.
- ◆ Inappropriate co-localisation of an adult in a paediatric ward.
- ◆ For subgroup of MPS individuals transition to adult health care supports the adolescents/young adults developing independence/personal development.
- ◆ Positive message about longer term health of that individual.

## ***What is the ideal process of transition?***

### ◆ What we want to avoid

- Abrupt transfer
- Staying in paediatric setting longer than is appropriate
- Leaving medical supervision altogether
- Falling through the gaps
- Avoiding the vulnerable period post transfer.

## ***What would be the ideal process of “transition”?***

- ◆ Planned and begun early
- ◆ Regular discussions between individual/family/carers of process
- ◆ Treating adult team identified
- ◆ Ability to meet this team before final transfer
- ◆ Clear understanding for patients so not in “limbo”
- ◆ Co-ordinated transfer of all specialists
- ◆ Transfer summary of medical history
- ◆ Medication



## ***What would be the ideal process of “transition”?***

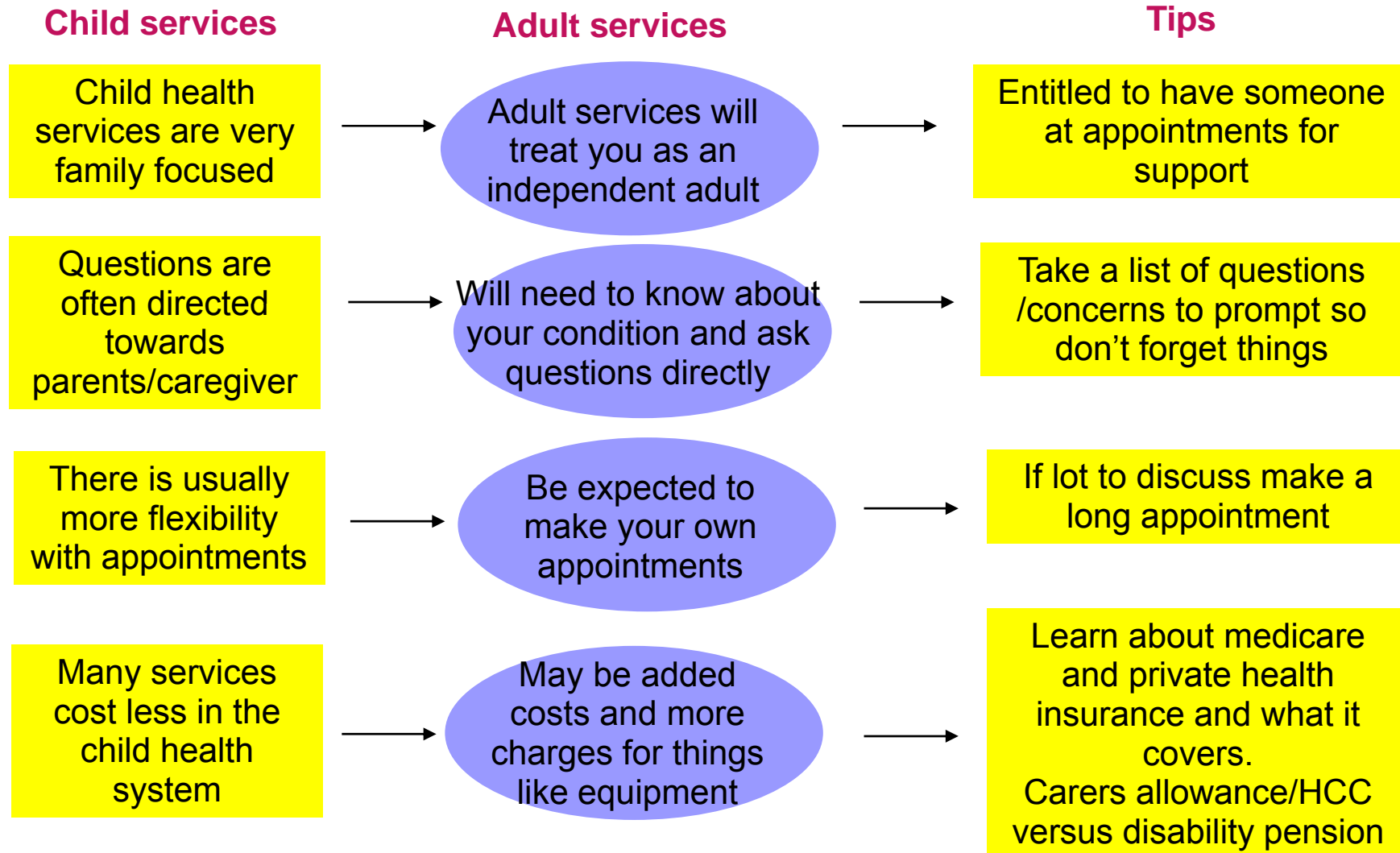
For individuals who will not be independent

- Encourage and facilitate the transition of whole family
- Support family to be advocates in adult setting

For individuals who will be independent

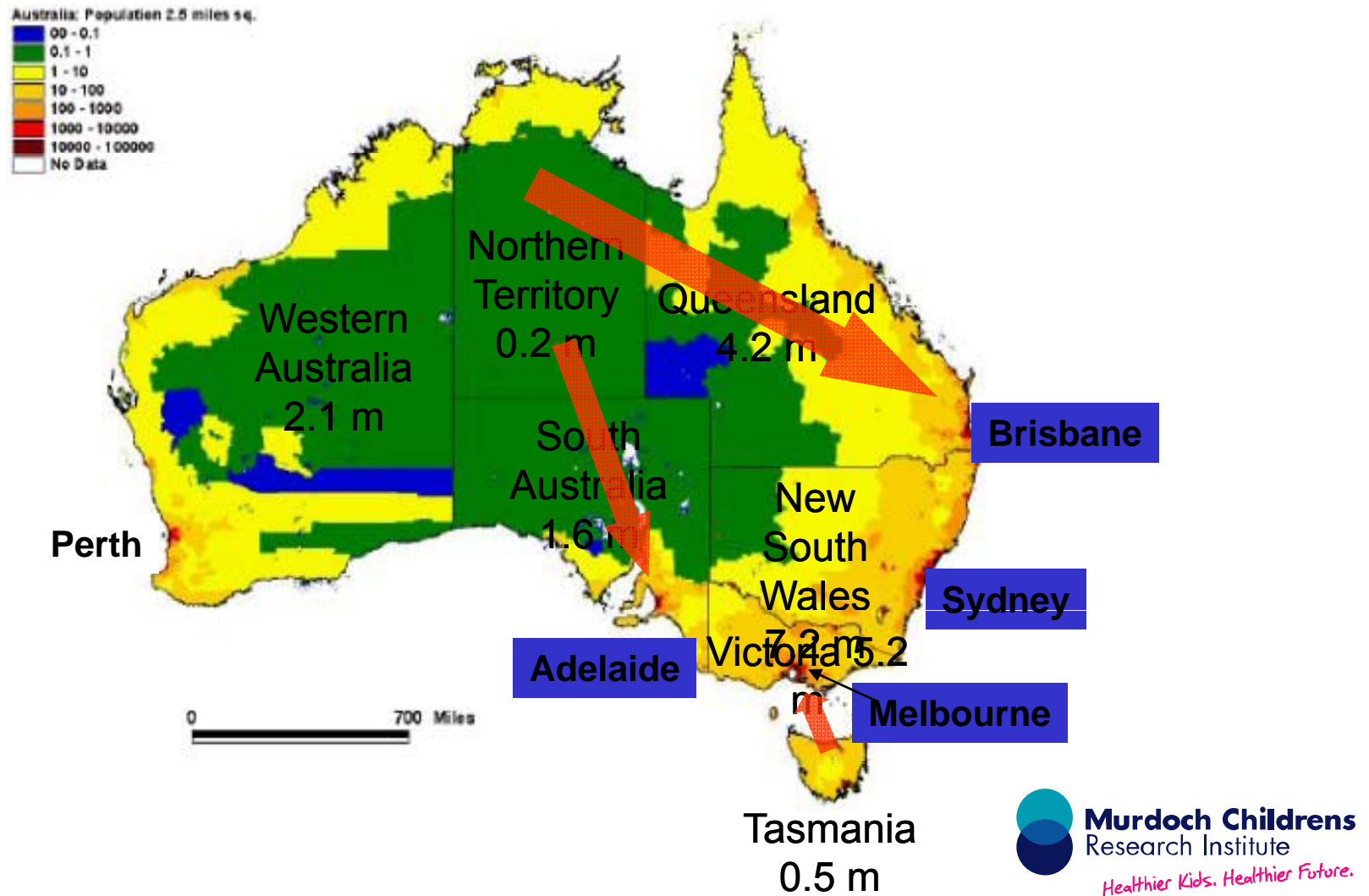
- encourage adolescent independence-”shifting in responsibility” and taking responsibility for their health- (appointments on their own, knows medication, knows emergency contacts etc.)

## What are the difference between adult and paediatric services?



## Paediatric Metabolic Services in Australia

- ◆ Different between each State.



## **Adult services**

### **What is currently available within Australia?**

#### Victoria

- ◆ Separate Paediatric and Adult hospitals
- ◆ Royal Children's Hospital has identified transition as an important issue
- ◆ Set up a working party with DHS funding in 2004.
  - Initial pilot program to transition young adults with complex medical needs- cerebral palsy and spina bifida.
  - Developed processes, protocols and information resources to help individuals, families and health care professionals in the process.
- ◆ Permanent transition coordinator to help facilitate the process.
- ◆ So far involved clinics with large groups of patients- eg diabetes/CF etc.

Website – <http://www.rch.org.au/transition>

## ***What is currently available within Australia?***

### Victoria

- ◆ Main problem has been lack of adult metabolic services to transition to!!!
  - “interested clinicians in these rare conditions are an endangered species”- Dr Jules Le Roy
  - Obtaining funding of a specialised multidisciplinary service is difficult.
- ◆ Adult metabolic service Monash Medical Centre mid 2009
- ◆ This year we are beginning to transition individuals with MPS and related conditions to the service.
- ◆ RCH policy- aiming for transition by 17-18 years of age with some flexibility (eg VCE year).
  - However the treating doctor is required to apply to the medical administrator for overage exemption (each time) if someone over age 18-19 is required to be admitted to the RCH because they have not been transitioned yet.

## ***What is currently available within Australia?***

### NSW

- ◆ Children's Hospital strict and require transition of individuals by 18 years. Treating doctor notified when individual is 17 years to commence process.
- ◆ Adult service at Westmead for adult lysosomal disorders for past 10 years. Aspects are not ideal as funding is limited- requires nurse coordinator etc.
- ◆ In past 2 years funding has been obtained to set up Adult genetic metabolic Services- making progress here.
- ◆ Specific training in adult metabolic genetics.

## ***What is currently available within Australia?***

### Queensland

- ◆ No specific adult metabolic service.
- ◆ Adult lysosomal patients managed by metabolic team within outpatient clinics for monitoring.
- ◆ Adults requiring admission/investigations admitted to an adult hospital under a medical team
- ◆ Metabolic clinicians go across to the hospital to consult and advise on metabolic aspects.

## ***What is currently available within Australia?***

### Adelaide

- ◆ Transition at 18 years
- ◆ Transition to Royal Adelaide Hospital
- ◆ Joint clinic run by adult specialist physician and metabolic clinician who goes across from the Adelaide WCH.

### WA

- ◆ No co-ordinated multidisciplinary clinic
- ◆ Individual clinicians care for individual patients.



## ***What are some of the difficulties in obtaining transition to an adult service?***

Attitude of

- ◆ Adolescent
- ◆ Family/carers
- ◆ Paediatric medical team
  - Mistrust of adult services and not wanting to let go
  - Long term attachment to a service and carers
  - Being comfortable with processes and knowing way around a system
  - Reluctance to negotiate a new system
  - Accelerated admission to emergency departments

## ***What are some of the difficulties in obtaining transition to an adult service?***

- ◆ Timing of transition in a degenerative disorder such as MPS conditions where an individual may be in end stages of their disease process in their mid to late teens or early adulthood.
  - Is it appropriate to transition their care? If so when should this be done- earlier or not?

## ***What are some of the difficulties in obtaining transition to an adult service?***

### Practical Aspects

- ◆ Lack of infrastructure
- ◆ Collaboration between paediatric and adult colleagues
- ◆ FUNDING OF SERVICES.
- ◆ Identification of practitioners willing/able to take over complex care needs of these individuals
- ◆ How do we train of adult clinicians in this “specialist” area?
- ◆ Geographical locality of services- (eg ambulance)

## ***Transition to an adult service in Australia***

### Summary

We have made progress – but we are really at the beginning and hopefully this will improve over next few years.



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## ***Acknowledgements***

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