Young People with Life-limiting Conditions: Moving from Child-centred to Adult-oriented Healthcare

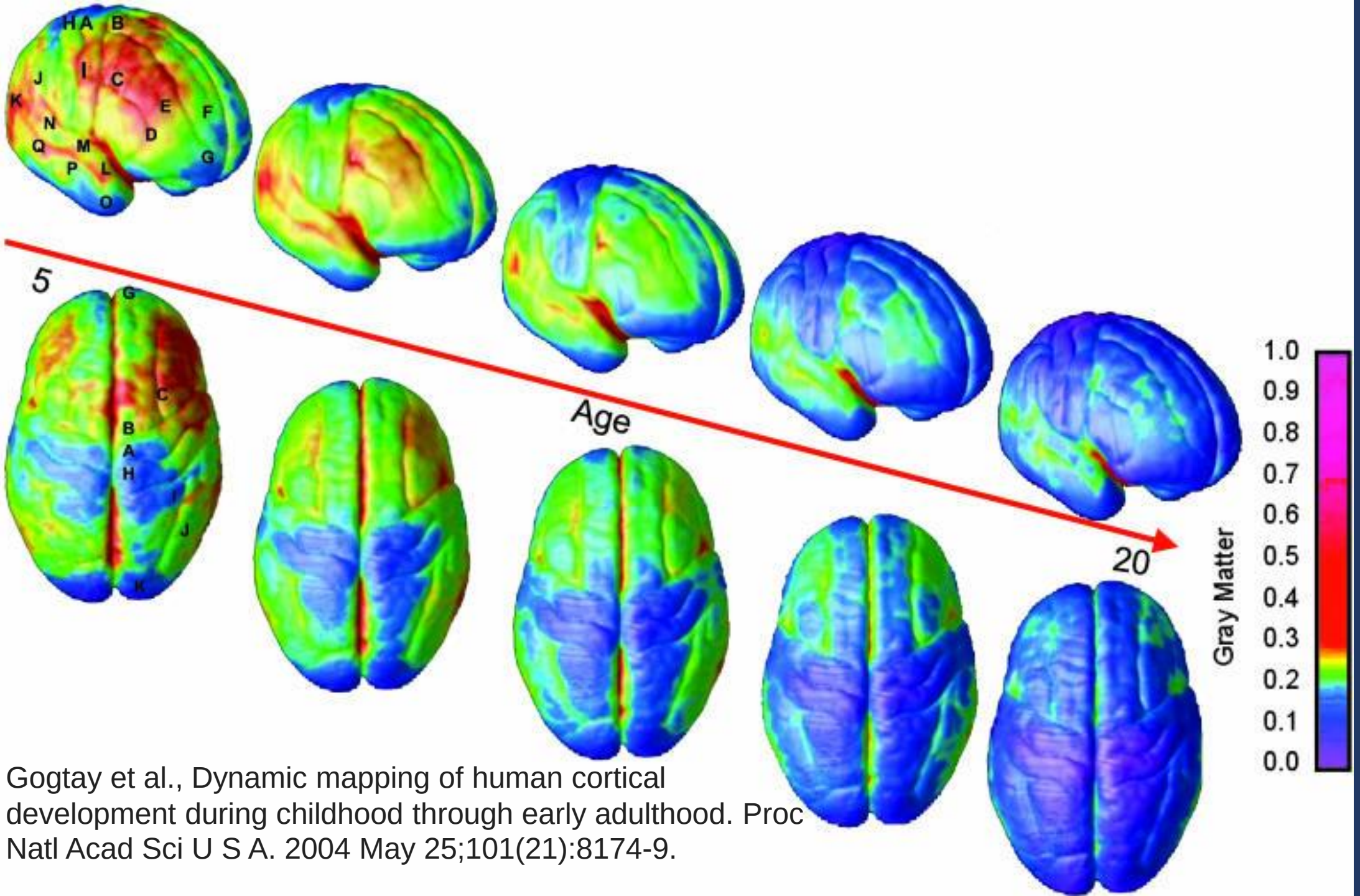
Archana Soman

NE&Y PEoL SCN Conference

12th October 2022

"ADOLESCENCE REPRESENTS AN INNER EMOTIONAL UPHEAVAL, A STRUGGLE BETWEEN THE ETERNAL HUMAN WISH TO CLING TO THE PAST AND THE EQUALLY POWERFUL WISH TO GET ON WITH THE FUTURE."

LOUISE J. KAPLAN



Gogtay et al., Dynamic mapping of human cortical development during childhood through early adulthood. Proc Natl Acad Sci U S A. 2004 May 25;101(21):8174-9.

Adolescence to adulthood: Multiple and Multidimensional Normative Life Transitions

- Physical
- Emotional
  - Evolving identity
  - Including sexual
- Education - Including career choices
- Social - Independent living, autonomy, relationships

Young adults with complex or life-limiting health conditions

- Non-normative transitions in almost all these areas

+

- ‘Other’ transitions

Jindal-Snape et al, 2017

‘Other’ Transitions in YA with LLC

- Health transitions
  - Healthy to unhealthy
  - Relative independence to relative or total dependence
  - Evolving illness and its effects – including progressive morbidity
  - *Outliving their life-expectancy – an ambiguous health status non-event (“we weren’t expecting her to be here now”)*

- Transitions between child-centred and adult-oriented services

Developmentally Appropriate Healthcare

DAH acknowledges the direct impact of
biological, psychological, social and vocational development
on the health or ill-health of YP

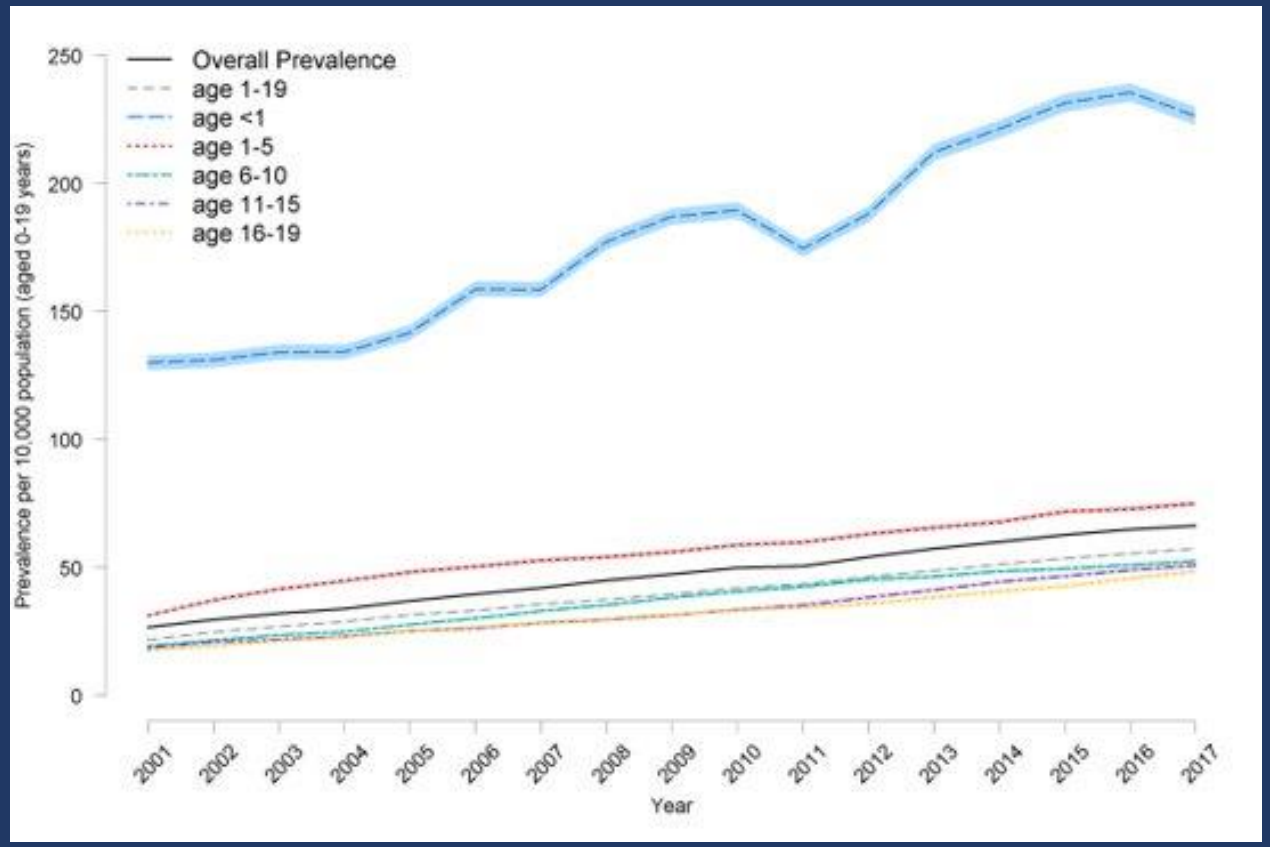
And thus the need to be responsive to changing needs

What is Healthcare Transition?

- A gradual process of empowerment, equipping YA with skills & knowledge to manage their own health care in paediatric/ adult services.
- Planned and purposeful movement of youth from comprehensive child-centred services to adult-oriented services
- A long process and not a brief/ single event – Not a transfer/handover

Why do we need to talk transition?

- Increasing prevalence of children with LLC: 2018: 66.2/ 10000
- Uncertainty - life-expectancy and morbidity
- Increasing complexity



Why don’t we just keep them in paediatrics?

- Young adults are not children, need to be treated as adults
- Adult services may be more age appropriate –
  - ❖Physical/ mental health needs are different
  - ❖Dignity, independence…
  - ❖Peers
  - ❖Choice, better access to services/ facilities closer to home
- Listening to young people – a mosaic approach

Jindal-Snape D, Johnston B, Pringle J, et al. Multiple and multidimensional life transitions in the context of life-limiting health conditions.. 2019;18(1):30. Published 2019 Mar 25. doi:10.1186/s12904-019-0414-9

Why do we need to talk transition?

- Quality of life during transition remains problematic
- YP/ family experience remain poor

- Highest mortality during transition
  - 85% of deaths in SCD after transition
  - Mean time to death after transition – 1.8 years

    Quinn et al, 2004

Lizzy – one of our ‘typical’ patients!

- Severe neurological impairment, fully dependent on cares
- Cared for by mum and dad
- Continuing Care care package
- Attends special school

Lizzy's problem list

- Epilepsy – GTCS, focal, myoclonic
- Global developmental delay
- Wheel-chair bound, completely dependent on care
- Cognitive impairment
- Visual impairment
- Dysmotility, visceral hyperalgesia
- PEJ fed, coeliac plexus block x 2
- Hypotonia/ hypertonia
- Scoliosis, hip dislocation
- Contractures
- Recurrent RTI
- Pain – multi-source
- Previous prerenal renal failure
- Neuropathic bladder, retention
- Deranged sleep

Lizzy’s medication list

- Lamotrigine
- Sodium valproate
- Clobazam
- Levocarnitine
- Riboflavin
- Lansoprazole
- Fentanyl transdermal
- Oramorph
- Dulcolax
- Movicol
- Loperamide
- Ranitidine
- Omeprazole
- Vitamin E
- Folic Acid
- Paracetamol
- Melatonin

Lizzy's professionals

- General/community paediatrician
- Paediatric neurologist
- Paediatric pall care consultant
- Paediatric gastroenterologist
- Paediatric ortho and spinal surgeons
- Paediatric surgeons
- GP
- Mitochondrial disease specialist
- Children's community nurses
- Paediatric epilepsy nurses
- Hospice nurses
- Physiotherapists, OT
- Dietitian
- School
- Carers
- Social worker

What do young people tell us?

Independence

Relationships

I'm a person, not an illness

Key worker

The burden of guilt

Education
Employment

Control/ownership

Talk TO me,
not AT or OVER me

Practical support

To experience!

Leisure

Psychological support

Yorkshire and Humber
Children's Palliative
Care Network

Hospice UK
Project ECHO®

What is helpful?

- Having support
- Being involved in discussions
- Professionals who are ‘genuinely interested’
- Explain processes
- General Practitioner being the ‘constant’
- Time to adjust
- Having parents alongside throughout

Yorkshire and Humber Children's Palliative Care Network

Hospice UK Project ECHO®

What is not helpful?

- New and complicated processes
- No-one taking responsibility
- Not being able to rely on help
- Not having introductions or even knowing who would be offering support
- Not knowing how to get referred
- Having to initiate their own appointments

Yorkshire and Humber Children's Palliative Care Network

Hospice UK Project ECHO

What do parents tell us?

- Listen!
- Relationships – consistency & coordination
- Who will fight our corner?
- Fears
- Resources
- The process

Yorkshire and Humber Children's Palliative Care Network

Hospice UK Project ECHO®

Parents' fears

Will we be excluded from decision-making?

Will we lose our supportive teams?

We will be lost

Yorkshire and Humber Children's Palliative Care Network

Hospice UK Project ECHO®

Paediatric professionals

- Long-term relationships
- Are we often overprotective? (GPs don’t get to know CYP)

- Fear that they may upset the YP/ family
- “Surroundings may not be age-appropriate”

Yorkshire and Humber Children’s Palliative Care Network

Adult professionals' concerns

- Lack of knowledge/ training - conditions/ pathways

  "out of my comfort zone", "don't know whom to refer to"
- Lack of resources: squeezing into existing services
- Silo working
- Lack of communication

Other challenges

- Different age cut-offs for different services
  - Hospitals – usually 16, up to 19
  - Community nursing – usually 18 -19
  - Children's hospices variable
  - Lack of clear professional networks/ pathways
- Differing guidelines/ policies/ information systems

Legal issues

- Mental Capacity Act
  - Best-Interests Decisions

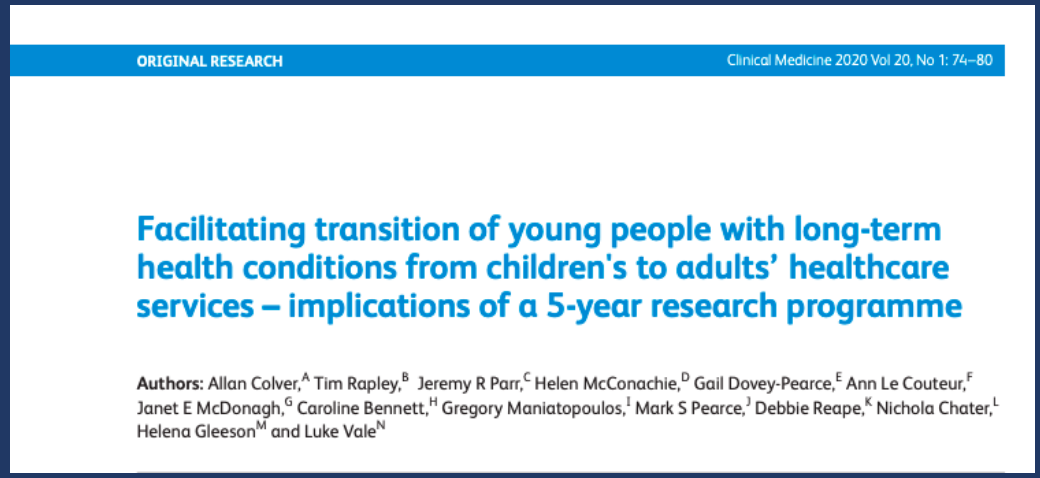
- Deprivation of Liberties Safeguards (Liberty Protection Safeguards)

Large number of professionals/ teams/ services in paediatrics

- Many without equivalent adult services

What helps

- Joint up planning
- Responsive and adaptable services
- Appropriate parental involvement
- Improving YP's confidence in managing needs
- Meeting the adult team before transfer



ORIGINAL RESEARCH Clinical Medicine 2020 Vol 20, No 1: 74–80

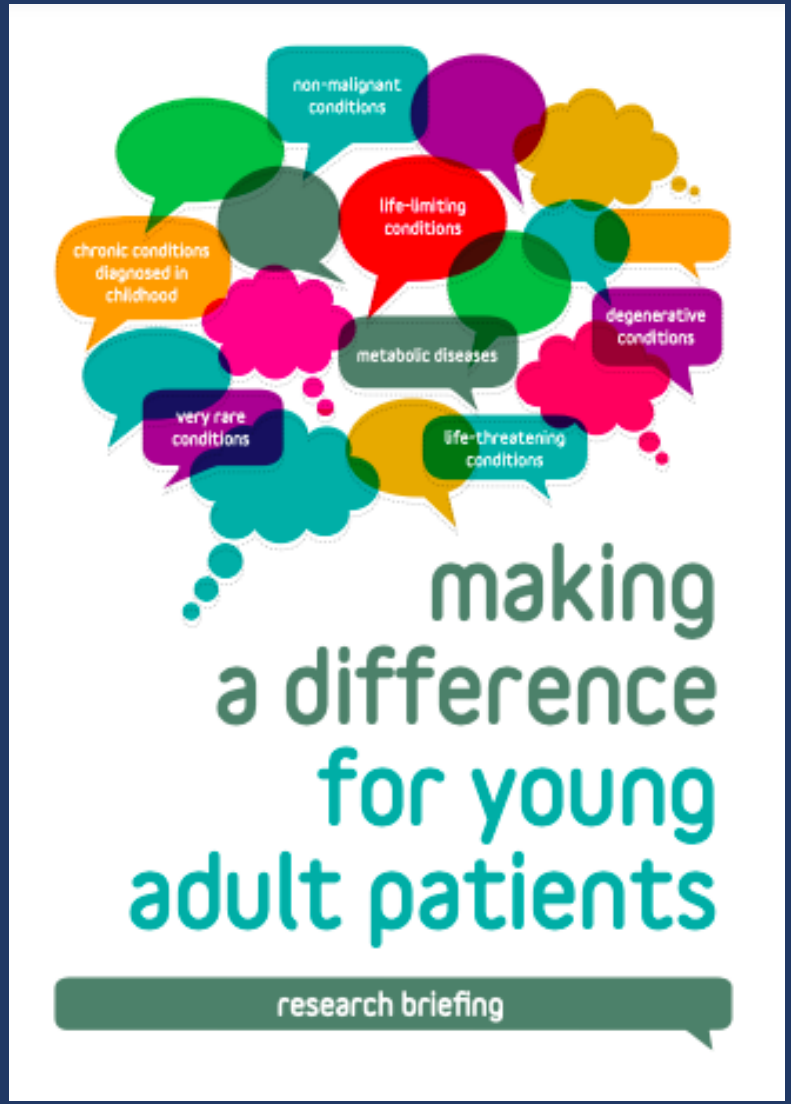
Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services – implications of a 5-year research programme

Authors: Allan Colver,[A] Tim Rapley,[B] Jeremy R Parr,[C] Helen McConachie,[D] Gail Dovey-Pearce,[E] Ann Le Couteur,[F] Janet E McDonagh,[G] Caroline Bennett,[H] Gregory Maniatopoulos,[I] Mark S Pearce,[J] Debbie Reape,[K] Nichola Chater,[L] Helena Gleeson[M] and Luke Vale[N]

Implications for funding: tailored services

The STEPP project (Beresford, 2013, TfSL)

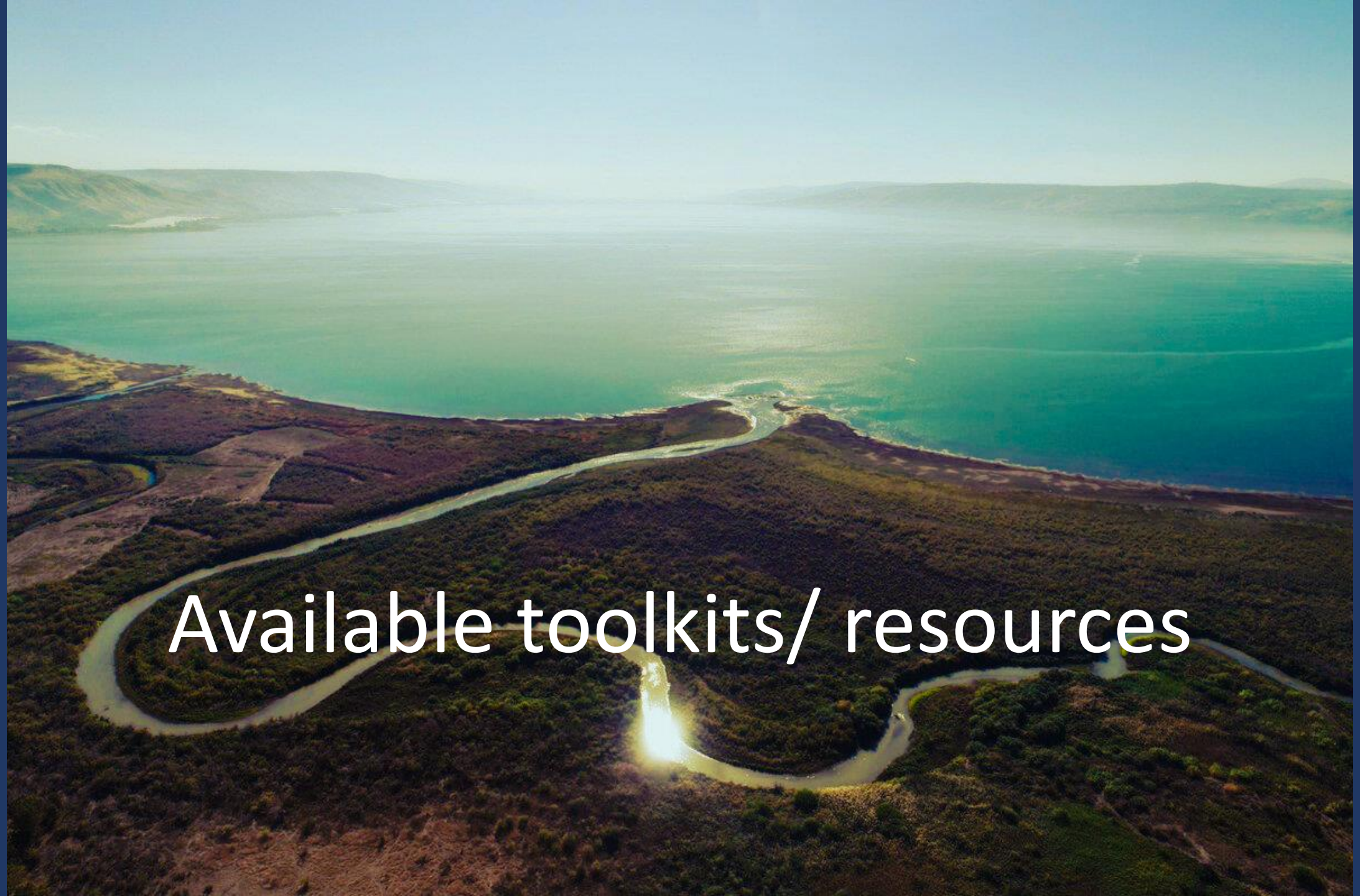
- Parental involvement
- Readiness for transition – ‘grown out’,
  wariness of the unknown,
  appreciation for flexibility, ’relationships’
- Inpatient experience –
  insufficient preparation, relative immaturity,
  lack of training of staff, assumptions about autonomy…
- Dealing with uncertainty – making plans
- Bereavement services



Clinical Medicine 2014 Vol 14, No 4: 404–8

Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions

Authors: B Beresford[A] and L Stuttard[B]


Available toolkits/ resources

Guidance/ Standards

- NICE Guidance Transition NG 43, Quality Standards 140

Quality Statements:

1. Early start 13/14
2. Key worker
3. Annual meetings
4. Meet professional from every team before transfer
5. Follow up if DNAs first appointment

- NICE Guidance Cerebral Palsy in adults: NG 119, QS 191

Stepping Up

- 3 Phases:
  - Preparing for adulthood
  - Preparing to move on
  - Settling in adult services
- Goals (5) -and-standards (30) based
- YP- centred throughout, family involvement
- Acknowledgement of uncertainties and
- Parallel planning and end-of-life care planning embedded in all phases

Diagram of the transition journey

Phase 1: Preparing for adulthood – Young Person age 14+

Young person

At the centre

Developmentally appropriate information

Supported to make decisions

Parents involved as young person wishes

Key worker

Friendships

Relationships

School

Service goals

1. Young people are at the centre of planning, using person-centred planning approaches.
2. Parallel planning takes place.
3. Initial conversations about transition take place with the young person and their family at a time and in a place that suits them.
4. A follow-up meeting with the young person and family takes place.
5. The first multi-agency/multi-disciplinary team meeting takes place.

Standards

Standard 1
Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services. Their families should be supported to prepare for their changing role.

Phase 2: Preparing for moving on – Young person aged 14-18

Young person

At the centre

Friendships

Relationships

Sexuality

Developmentally appropriate information

Advocacy

Self-advocacy

Self-management of condition

Short breaks

Service goals

1. Young people and their parents are helped with the transition from family-centred to young person centred-care.
2. Every young person has a key worker to facilitate continuity of care and prepare the way into adult services.
3. Every young person is supported to consider future plans, supported by ongoing multi-agency assessment.
4. Every young person is supported to identify adult services which can meet their needs.

Standards

Standard 2
Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.

Able to talk about wishes for future

1. Transition planning continues to take place even during times of uncertainty.
2. Every young person has a documented end of life plan running alongside their plan for future life.
3. The young person's pain and other symptoms are dealt with effectively.
4. Every effort is made to ensure that the young person's death takes place

Standard 3
Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.

This standard applies to all stages of the transition journey.

Standard 3: Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in

Standard 3: Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in

Phase 2: Preparing for moving on – Young person aged 14-18 (continued)

Young person

Service goals

8. Siblings should be supported and included in all decisions.
9. All professionals/agencies should be informed of the death with the parents' consent.
10. All family members should be supported according to their individual needs for as long as they need it.

Standards

Keyworker supporting all aspects of the move to adult services

1. Child and adult services within health work together so that there is an overlap of care planning and care provision.
2. Services within all agencies should be engaged in planning for the specific needs of the young person.
3. Ongoing reviews (at least annually) with the young person take place.

Standard 4
Children's and adult services are actively working together to enable a smooth transition.

Phase 3: Settling in to adult services – Young adult age 18+

Young person

Friendships

Relationships

Sexuality

Self-management of condition

Meaningful occupation (leisure, education, work)

Short breaks and holidays

Technology and adaptations

Independent living

Support in using personal budgets and managing personal assistants

Service goals

1. A key working function is provided for every young person so that all the agencies providing care and support are co-ordinated.
2. All agencies ensure that age and developmentally appropriate services are available that address the full range of a young person's needs.
3. Palliative care services provide a single clinical overview for the young person and link with other specialists involved in their care.
4. There is frequent review and communication across services about care plans and end of life decisions.
5. Primary health care services, including GPs, develop a relationship with the

Standards

Standard 5
Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.

Transition MDTs

- The voice of the YP/ Family is heard
- Everybody gets to know the unique strengths, wishes, needs and challenges
- Processes are carried forward
- Finding the right personnel/ services
- Getting to meet new professionals, teams; see areas, services
- Reviewing progress
  - Addressing previously unanticipated challenges

Child and Young Person's Advance Care Plan Collaborative

Endorsed by NICE

This plan could begin antenatally

ALLERGIES

Nursing and Medical staff please look at my Passport before you do any interventions with me.

NHS
The Rotherham
NHS Foundation Trust

My Health Passporx

RED– Things you must know about me

Amber– Things you need to know about me

Green– Things you should know about me

Paediatric to Adult Critical Care Transition Pathway

Patient details

Name
DOB Hospital number
NHS number
Address

Paediatric to Adult Critical Care Transition Checklist

Way points	Yes/No	Target date or date of completion	Relevant details	Completed Yes/No
Paediatric speciality transition commenced	y			
Handover occurred from paediatric to adult critical care commenced PICU Consultant:	Na			
PICU Nursing:	Na			
Psychology:	Na			
Physiotherapy:	Na			
Pharmacist:	Na			
Dietician:	Y			
Home ventilation	Na			
Patient and family /	Yes			

Summary

- Increasing numbers with LLC surviving into adulthood
- Complex transition needs – health services, but also social, psychological, developmental and educational
- Developmentally Appropriate Care
- Gradual MDT process with YP at the centre
- *Key Workers*
- Flexible adult services adapted to specific needs

Summary

- Paediatric and adult services and professionals
  - differing yet complementary skill sets.

- Working together aids:
  -Better understanding of available services
  -Transference of skills and knowledge
  -Improved experience and seamless transition of care

archanasoman@nhs.net
Twitter: @archsom