## **Transition Research Programme**

**Implications for Senior Clinicians**

Young person with cerebral palsy: *“It was like once I turned 18 I kind of didn’t exist to them at all, that was it. So there wasn’t anything done”.*

NHS Clinician/Commissioner: *“What we’re now doing is making sure that we include in all the contracts for the adults’ services that they must be involved in transition.”*

**What is meant by ‘Transition’ and ‘Transfer’ of young people?**

These two terms are often used interchangeably but in fact refer to different things.

**‘Transition’** is the purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with long term conditions as they move from child-centred to adult-oriented health care systems.

**‘Transfer’** is the formal event when the healthcare of a young person moves from children’s services to adult services.

**Why is Transition important?**

* The number of young people in transition to adulthood is increasing; many children with long term conditions, who now live into adulthood, might previously have died. In an NHS Trust serving a population of 270,000, about 100 young people with long term conditions reach age 16 each year. As transition takes place over about 7 years, the number in transition at any time in a typical Trust is about 700.
* There are risks if transition is not successful. Disease control, continuity of healthcare, and co-ordination of care are compromised; and the outcomes of: healthcare costs in later life, social participation, and employment or further education are often poor.
* Recent understanding of how much the brain changes during adolescence explains why adolescents behave and react differently to children and adults
* Adult services for some groups are not routinely provided, such as for Adults with Attention Deficit Disorder
* Unless specifically commissioned, arrangements for promoting successful transition can fall all too easily between child and adult services and so not be provided

**Transition in the UK**

There is an expectation that transition should improve and that this is the shared responsibility of commissioners, providers and clinicians. Recent policy includes:

* Central government guidance for 10 years e.g. ‘Transition: moving on well’, DH, 2008
* Kennedy Report 2010. Recommendation 32 about commissioning for transition
* Care Quality Commission ‘From the Pond to the Sea’, 2015
* NICE Guidance, 2016

**The 5-year NIHR funded research programme on transition**

We completed an NIHR funded Programme of Research into Transition in October 2017. On the next page are implications of our work which may be relevant to senior clinicians. PTO

**Implications for Senior Clinicians**

A summary of all our results and their implications are on our website <http://research.ncl.ac.uk/transition/> Some research articles (downloadable from our website) are published and more will follow. The full report published by NIHR may take up to a year to appear.

* **Ensure that transition arrangements are planned simultaneously with adults’ services as well as children’s.**

Currently transition is regarded as the responsibility of child commissioners to commission and of child services to provide – this is not correct because Transition continues to approximately age 24. Until attention is paid to both adults’ and children’s services, outcomes will not improve for young people with long term conditions.

* **Introduce ‘Developmentally Appropriate Healthcare’ across all Trust services (hospital and Community), with responsibility resting at Chief Executive/Board level.**

Developmentally Appropriate Healthcare (DAH) is the subject of a toolkit we have developed where it is defined and which is a resource for education and training. [https://www.northumbria.nhs.uk/dahtoolkit](https://outlook.office365.com/owa/redir.aspx?REF=zr4qwnG3IbM9I_eL1myP_K0t5iJOgvgk7o4q-jJJx-kmbQ2jNA7VCAFodHRwczovL3d3dy5ub3J0aHVtYnJpYS5uaHMudWsvZGFodG9vbGtpdA..)

One important element of Developmentally Appropriate Healthcare is that young people, in both child and adult services, should be seen by themselves for at least some of the consultation. However, our research showed that involvement of parents in a manner which suits both parties (this will vary between different young person/parent dyads) led to better outcomes – in terms of satisfaction with services, disease control, continuity of healthcare and maturation to adult roles. This applies in adults’ services, not just children’s services. Provided a young person gives permission for a parent to be present for some of the consultation, there are no confidentiality issues.

Training in Developmentally Appropriate Healthcare will need to be provided

* **Ensure arrangements are in place across all specialties for a young person and family to meet the adult team before transfer.**

Our research showed that meeting the adult team before transfer of healthcare led to better outcomes.

* **Ensure that promotion of health self-efficacy is a feature of all consultations.**

Our research showed that a formal approach to promoting a young person’s confidence in managing their health condition (health self-efficacy) was associated with better outcomes.

* **Paediatric and adult healthcare professionals may wish to develop an individualised approach to the transition of each young person using a new finding of our research.** We found young people were likely to adopt one of four styles when approaching their transition: ‘being laid back’, ‘being anxious’, ‘seeking autonomy’ or being ‘socially-oriented’ (welcoming support from and frequent discussions with family, friends and clinc staff).