## **Transition Research Programme**

**Implications for Commissioners: CCGs & NHS England**

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. One research stream investigated the challenges of commissioning for transition. On the next page are implications of our work which may be relevant to commissioners. PTO

**Implications for Commissioners: CCGs & NHS England**

Implementation of our recommendations is likely to improve the outcomes for young people with long term conditions and reduce the risk of medical complications.

We are not recommending new or additional services, nor in general a move of resources between budgets; rather a change in clinical practice in both children’s and adults’ services.

Successful transition is a priority for all children with long term conditions; not just the small group of young people with very complex needs who require integrated commissioning across CCGs, Health and Wellbeing Boards, Education and Social services to fund bespoke multiagency packages of care.

* **Ensure that transition is commissioned for adults’ services as well as children’s.**

Currently transition is regarded as the responsibility of child commissioners to commission and of paediatric services to provide – this is not appropriate as Transition continues to approximately age 24.

* **Where an adult service to which to transfer young people with a specific long term condition is not commissioned, commissioners should state explicitly the transfer arrangements (usually to primary care), and require appropriate documentation and assistance to the young person to make their first appointment.**
* **Commission for a framework to provide ‘Developmentally Appropriate Healthcare’ across all Trust services (hospital and community) and stipulate that this is owned at Chief Executive/Board level.**

Developmentally Appropriate Healthcare (DAH) is the subject of a toolkit we have developed in which DAH is defined and which is a resource for education and training.

An important element of DAH 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 shows that involvement of parents in a manner which suits both parties (and this will vary between different young person/parent dyads) leads 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.

* **Commission for NHS organisations to adopt a Trustwide approach to implementation of better transitional care.**

A Transition Steering Committee, with a Trustwide Transition Coordinator, can facilitate this.

All the above is consistent with the **NICE Guidance on Transition (ng 43, February 2016)**. However, our recommendations are fewer in number and supported by evidence from our research.