## **Transition Research Programme**

**Implications for Department of Health**

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

**Implications for Department of Health**

In determining policy, the Department of Health should consider the implications of this Research Programme, which are summarised below. We have already published research papers from the Programme and more will follow.

A summary of our results, their implications and published papers are on our website <http://research.ncl.ac.uk/transition/> We have also submitted our Final Report to NIHR.

We were determined to present a document with a small number of practical implications, rather than a long list of guidance, much of which might be aspirational or lack an evidence base. We were advised in discussions with commissioners and senior NHS managers during the Programme, that such a document would be easier to grasp and implement than longer reports.

* Transitional care should be commissioned by commissioners of adult services as well as by commissioners of child services.
* A framework to provide ‘Developmentally Appropriate Healthcare’ across all Trust services (hospital and community) should be commissioned, with the stipulation that this is owned at Chief Executive and Board level.
* NHS Trusts should adopt a Trust wide approach to implementation of transitional care. A Transition Steering Committee, with a Trustwide Transition Coordinator, can facilitate this.
* We found that a young person is likely to adopt one of four styles when approaching their transition: ‘laid back’, ‘anxious’, ‘seeking autonomy’ or ‘socially-oriented’ (welcoming support from and frequent discussions with family, friends and clinc staff). This provides an important opportunity for child and adult healthcare professionals to adopt an individualised approach to the transition of each young person.
* We found the following three features of transitional care were associated with better outcomes: ‘Parental involvement that suited both young person and parent’, ‘Protocol for promotion of young people’s confidence in managing their health condition’, and ‘Meeting the adult team before transfer’. Effort should be directed to delivering these well.
* Maximal service uptake would be achieved by a service which encouraged parental involvement, ensured the same staff were seen at each clinic and encouraged young people to make decisions about their care. Good value for money would be offered by a service which provided ‘Parental involvement that suited both young person and parent’, and a ‘Protocol for promotion of young people’s confidence in managing their health condition’ may offer

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.