## **Transition Research Programme**

**Implications for Young People with long term conditions in transition**

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”.*

**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 reports Oct 2017**

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 of interest to you. PTO

**Implications for young people in transition with a long term condition**

* **There are three features of transition services which really seem to make things better for young people. We are advising that health services should concentrate on them – and you may wish to ask about them and expect them. They are:**

i) Both adults’ and children’s services should give you the opportunity to talk with your doctor or nurse by yourself. However, especially in the adult service, you should say whether your parent(s) could also meet with the healthcare staff. If you and your parent(s) are both up to date with the advice from the health staff, this can make it easier for everyone. However, if you prefer your parent(s) not to join part of the consultation that is fine because you must feel comfortable with the arrangement if it is going to work.

ii) It is helpful if you and your parent(s) can meet the adult team before you transfer across. This can reduce your anxieties and improve communication between the staff in the child and adult services.

iii) You should be being helped and encouraged to take responsibility for the care of your health condition. This should happen gradually and at a pace that suits you. The healthcare team should be talking about this with you regularly and asking you in what areas you feel confident or not so confident. Think about how to navigate the new service as well as how to manage your own condition.

* **We undertook a study which involved asking young people to put in order of importance statements about transition.**

We found a young person usually adopted one of four approaches to transition and it would be worth discussing yours with your health team. Some young people are *pretty laid back and relaxed about transition.* Some are *anxious about transition*. Some *really want to be in control and lead what is going on*. And the final group, which overlaps a bit with the others, is called *socially oriented. The young person really likes other people to be involved and helping, whether it is close family, friends, or all the nurses and doctors in the clinic.*

* **You might like to look at our website. There are sections for young people. You would also see all the work that the young people’s advisory group did in assisting with all the research. This group calls itself UP.** [**http://research.ncl.ac.uk/transition/**](http://research.ncl.ac.uk/transition/)
* **You might like to look at a toolkit we developed for senior managers and doctors and which is also on the website**

The toolkit is about *Developmentally Appropriate Healthcare*. This is a bit of a mouthful but essentially it means that young people are neither children nor adults. Young people change in many ways between the ages of 12 and 24 and healthcare staff must show young people that they are aware of the changes occurring in their lives. Also healthcare staff need to help young people to feel confident, by having discussions in consultations about how young people can gradually take on responsibility for their health.