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Dear Parent

**Transition Research Programme**

This project which you and your son or daughter joined has now completed and we are using the results to try to bring about change in the NHS.

We have sent your son or daughter a newsletter with the results in it. I am very pleased to enclose for you a brief summary of what we think the implications of our research might be for parents.

Yours sincerely



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## **The 5-year NIHR Funded Transition Research Programme reported in October 2017**

**Implications for Parents of young people with long term conditions in transition**

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I had to write to all of the individual services, and say, ‘Ben is now 18. What do we do?’ And a, a couple of them I had to chase up a couple of times, to just get letters back saying, ‘Right, you just ring them.’ And that was it, literally. So nobody even sort of came to see us, to say, ‘Bye bye, this is where you go.’ It was just literally nothing, and we had to write to everybody to say ‘Ben is now 18. Can you point us in the right direction?’

(Parent of young man with cerebral palsy)

* **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 your son or daughter the opportunity to talk with their doctor or nurse by themselves. However, especially in the adult service, your son or daughter may want you to be there for part of the consultation; and you may want to be there as well. The adult team must make this option available but it is your son or daughter who decides what should happen.

This may be something worth discussing at home, in between appointments. Our research did find that if both you and your son or daughter are happy with the arrangement, then this makes transition easier. The arrangement may be that you do or do not join part of the consultation. The arrangement will also change. It is likely your son or daughter will be arranging and travelling to appointments by themselves by the time they are, let’s say, 25 years old.

**ii)** It is helpful if your son or daughter and you can meet a member of the adult team before the transfer takes place. This can reduce your anxieties and improve communication between the staff in the child and adult services. If your son or daughter is being discharged to care by the GP, a similar arrangement should be made.

**iii)** Your son or daughter should be being helped and encouraged by the health team to take responsibility for their healthcare. This should happen gradually and at a pace that suits the young person. This means that you also need to adjust. When your child was little, you had to take all the responsibility for their healthcare. You will remain a source of knowledge and help for your son or daughter but eventually he or she should take over making appointments, monitoring their health and making their own judgements about risks.

* **You might like to look at our website. There are not any sections specifically for parents, but you can read about the programme, see all the work that the young people’s advisory group did in assisting with the research, and you can see summaries of the results.** [**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.

**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 with many more children with long term conditions, now living into adulthood. 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 can be 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