

Preliminary Findings from Year 1 of the Longitudinal Study

The longitudinal study follows the progress of 375 young people over three years, as they go from child healthcare to adult services. The young people are visited each year by a local researcher and we now have some findings from the first of the visits to share with you.

Who is taking part in the study?

There are more young men taking part than young women: 59% male and 41% female. All the participants are between the ages of 14 and 18 years 11 months, and for each a parent is also involved. The young people have one of three health conditions: Autism Spectrum Disorder (with additional mental health service involvement) (32%), Cerebral Palsy (28%) and Diabetes (40%). At the time of entering the study, all the young people were under the care of child or adolescent health services, at 10 sites across England and N. Ireland.

Views about Health Services

372 young people and 364 parents / carers completed the 'Mind the Gap' questionnaire, which compares perceptions of 'best' and 'current' care to work out how satisfied a person is with the service received. A high score indicates a large gap between best and current care (and thus dissatisfaction with current services.)

The questions fall under three broad headings:

- Environment e.g. displays age appropriate materials in waiting areas
- Interpersonal skills e.g. having staff who know the young person well
- Administration e.g. providing appointments at times which are convenient

We thought that some types of health services might be better than others; however, we found no association between a young person's condition and their satisfaction with their healthcare services. Interestingly there was a gap between young people's satisfaction on average and those of their parents. The parents were *less* satisfied with current services than their child was in at least two areas (ASD) or across the board (diabetes and cerebral palsy).

Wellbeing

Young people completed the Warwick-Edinburgh questionnaire on mental wellbeing. We expected that young people with ASD would report lower wellbeing than the other groups, as that was part of the reason for their contact with healthcare services. And that is what we found. This shows that the questionnaire is valid as it picks up this important comparison.

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Overview of well-being

Condition	Total Mental Wellbeing Score	
	Mean	Median
Autism Spectrum Disorder	46.1	47
Cerebral Palsy	52.7	53
Diabetes	52.3	53

Participation

The research team are keen to know how young people take part in everyday life. Using the Rotterdam Transition Profile, the longitudinal study is examining levels of independence and social participation across the three condition groups. Recognising that young people may be more independent in some areas of their life than others, the questions cover a range of subjects or 'domains' such as employment, romantic relationships and leisure activities.

The responses given by the young people against each question fall into one of three developmental phases:

Phase 1. Tending to be dependent on parents

Phase 2. Experimenting and orientating with the future

Phase 3. Independent life and decisions

Data from the first visits showed that in many of the domains, young people with diabetes tend to be moving further towards independence than those with cerebral palsy or ASD. Nevertheless half of the young people with ASD are independent in their leisure time choices. And two thirds of young people with diabetes still largely depend on parents for transport. The most interesting questions will be about changes over time in independence.



Some Feedback from our Q Sort Study

The Q-Sort study examines young people's views, opinions and beliefs on transition services. We recruited over 40 young people with a wide-range of long-term health conditions from clinics at Newcastle upon Tyne Hospitals. We asked them about successful transition, and tasked them with placing a series of statements about transitional care into order of importance *to them*.

Preliminary Findings

From analysing 41 young people's responses and priorities, we were able to identify 4 broad categories of viewpoints. Some young people (44%) were associated with two or more groupings. The main viewpoints identified were :

- ◆ Laid-back group (19 young people)
- ◆ Anxious group (12 young people)
- ◆ Autonomy seeking group (8 young people)
- ◆ Socially oriented group (18 young people)

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As the name suggests, the “**laid-back group**” were relaxed about transition and not particularly interested in it.

My condition doesn't interfere much with my daily life and I don't need much support. When it comes to visiting the doctor, I'm happy to have my mum in the consultation room with me. I'll sit and listen to what my doctor has to say, but I'd prefer to get my information in more varied ways

In contrast, the “**anxious group**” were worried about transition. They felt ‘attached’ to staff and wanted to build up trust with their clinicians. They were worried that, even if they met new staff before transfer, it would still be difficult. They found their condition difficult to live with and predicted they would need extra support in future. They wanted a written transition plan, and a service that could also cater for their friends and family's needs, and they wanted their parents to remain involved in their care.

The “**autonomy-seeking group**” wanted clinical staff to encourage them to make their own care decisions and to prepare for independent living. They anticipated staff in the adult clinics would give them the same standard of clinical care. They were worried they might be discriminated against because of their condition.

I feel ready to move to a more grown-up environment without all the teddies and kids' stuff. I don't need my parents in the room with me, but it might be helpful to meet with the adult team before I formally transfer.

The “**socially oriented group**” wanted to meet other young people of similar age with similar conditions, and they wanted a key worker. They wanted continuing involvement in their care from their parents, and felt it was important that staff were interested in other aspects of their life as well as their health. They thought staff should mention teenage issues such as smoking, drugs and sex. They thought their condition affected all areas of their life and that they would need extra support in future; they did not worry that they would be discriminated against.

So how does this research help us?

In a clinical setting the results may help guide discussions with young people about their particular preferences in terms of how they will soon transfer to adult care.

As researchers, we will use this information to gather further data on how young people might weigh up different ways of receiving transition services. For example, how much more important do young people think it is to have a good relationship with the staff than to be able to attend a clinic outside of normal office hours? These findings will be crucial to making recommendations about transitional care that are informed by young people's preferences.

For more information on any of our research email transition@ncl.ac.uk or visit our website <http://research.ncl.ac.uk/transition/index.html>



UPdate

News from the Programme's young people's working group, 'UP'



The young people's working group makes a huge contribution to the Programme. Made up of 26 young people, the UP group provides regular help and advice. From speaking at the Programme launch event, to advising researchers on detailed aspects of the studies, they are involved at every level of the Programme. Right now, UP is also conducting its own pilot study into the use of health passports.

So while it's clear what the Programme gains from having a young people's working group, we wanted to find out what the young people get out of their involvement in the Programme. The responses we received from the group are eye-opening, and they show a group of dedicated young people, committed to improving the futures of other young people with long-term health conditions.

Here's just a couple of the comments we received:

"Hello, I'm Jonny and I enjoy being part of United Progression because of the change that will happen because of the work we will do over these 5 years."

- Jonny

"Hello, I'm Joseph – I'm 21 years old and have Asperger's Syndrome which is an autistic disorder. My favourite bits of UP have been the Launch Event where I gave a brief speech and the teleconference where I asked a couple of questions to the specialists via the recorder. I've really enjoyed coming to UP. The work is always positive and we are optimistic about making a difference to young people."

- Joseph

To read more about what the UP group had to say, visit our website:

<http://research.ncl.ac.uk/transition/Blog.html>

Events of Interest

- **June 16-17th 2014— International Association for Adolescent Health**
Paris
www.iaah-paris2014.org
- **September 10-12th 2014— BSA Medical Sociology Annual Conference**
Aston University
www.britsoc.co.uk/events/medsoc-annual-conference.aspx
- **October 1st 2014— International and Interdisciplinary Health Care Transition Research Consortium (HCTRC) - 15th Annual Chronic Illness and Disability Transition from Paediatric to Adult Care Conference**
Houston, Texas

The Transition Research Programme is independent research funded by the National Institute for Health Research (the research arm of the NHS) under its Programme Grants for Applied Research funding scheme (RP-PG-0610-10112).

The views expressed in this newsletter are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.