TRANSITION

NEWSLETTER Issue 2 June 2013

Transition Celebrates Its First Birthday

Update by Sarah Nolan, Programme Administrator

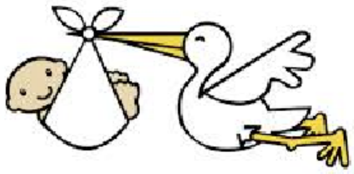
On 1st May the Transition Programme celebrated its first birthday. Its been a busy 12 months for the Programme, but we've made some great headway. Some of the highlights include:

- Recruiting 207 young people to the longitudinal study. Its really great to hear some of the positive feedback from young people and their families about why they are getting involved in the study. But it also reminds us why improvements to transitional care are so needed. (There's more information on page 2)
- Successfully forming a young people's working group called UP, which offers advice and oversight to the Programme. (Their latest update is on page 3).
- Starting recruitment to the YETI study, which takes a more in-depth look at young people's experiences of transition. (There's more information on this study on page 3.)
- Beginning to find out from young people what features of transitional care are beneficial to them and their families.
- Putting in place suitable arrangements for governance and oversight, including a Programme Management Board, Publications Committee and External Advisory Board, which offers independent scrutiny and advice.

Obviously, with 4 more years of the Programme to go, there is a lot more we want to achieve. Current work in the pipeline includes a review of health passports by UP, and a look at developmentally appropriate healthcare. Researchers are also starting to interview health professionals about the barriers to organisational change within the NHS.

But at the end of the first year, we would like to say a big thank you to everyone involved in the study. In particular, thank you to the young people for sharing their experiences with us!

Inside this issue



CONGRATULATIONS! to Transition researcher Hazel Windmill (Wexham Park) on the birth of twins.

Take a look at the Transition blog:

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

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).

Newcastle University

Northumbria Healthcare NHS
NHS Foundation Trust

Transition News

Spotlight on Transition Issues

The Social Policy Research Unit (SPRU) at York University recently published its report **'Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions'.**
The report examines ways in which young people with ASC (including those with high functioning autism and Asperger's syndrome) are supported over the transition period and into young adulthood. It also sought to understand and describe the experiences of young adults and their parents during this period. To view the report, visit: http://php.york.ac.uk/inst/spru/pubs/2371/

Cerebra are holding Managing Transition seminars in Manchester and Newcastle (25 & 26 June). The subject is 'Disabled children and their transition into adulthood: the law and good practice'. For further details see http://www.cerebra.org.uk/ENGLISH/WHATSON/Pages/Managingtransitionsseminar.aspx

25th European Academy of Childhood Disability

Logo designed by Thomas Bewick School

This three day conference will be hosted at The Sage in Newcastle-Gateshead from **10th-12th October 2013.** The EACD conference is the largest annual paediatric neurodisability conference in Europe, and was last held in the UK in 2003. For further information see http://eacd2013.org/

A big thank you to our research participants on the longitudinal study! We've now reached 200 recruits!!

From Allan Colver and Helen McConachie

The longitudinal study is going really well. 200 young people have now joined it and we hope you realise just how helpful and important your involvement is.

It is the first study ever where young people will be followed as they progress through transition. Therefore you will be able to say what it is like going through transition, rather than just being asked at the end.

You have kindly agreed to complete questionnaires once a year; and for the research associate to be kept aware of your whereabouts – whether moving home or going to college etc.

We would like ideas from you about what would be interesting to receive or be told about. Some of you may just want the newsletter whilst others might want more detailed regular information and news. You will be receiving this newsletter from the research associate that you work with so just let them know what you'd like more of.

Please visit the website if you want more information about other parts of the research

http://research.ncl.ac.uk/transition/index.html

Programme Update

YETI—Young People's Experiences of Transition

YETI is taking an in-depth look at young people's experiences of transition. 15 young people will be recruited to the study from the larger longitudinal study; 5 people from each of the groups (ASD, cerebral palsy and diabetes.)

The study will use a mixture of methods to understand each young person's experiences of transition over a 2-year period including:

- Interviews with the young people, members of their family, boyfriend/girlfriend or friends and clinicians
- Observation of a few consultations with their clinicians
- Asking the young person to keep a diary. They can do this through taking photographs, making video clips, writing a diary or talking into an audio-recorder

Recruitment to this study is underway, with the first young people and family members interviewed in March 2013. Participants are from across the UK, with the hope that all of the 9 Programme sites will be represented.

For further information please contact Research Associate Rose Watson:

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UPdate

Established early in the research, **'UP'** is the young people's working group for the Transition Programme. Group members, all of whom have experience of accessing secondary healthcare services, meet monthly. They meet on an early evening, have a meal together, discuss any matters arising and carry out their current tasks.

Their role is to represent the voices of young people in the programme, by working in partnership with the Programme Management Board, influencing decision making. Their tasks are central to the running and delivery of the programme. They are currently exploring their own questions around the concept of 'health passports'.

They are keen to explore and describe issues with health passports currently in use, rather than create another version to add to the many already in existence. They hope to be able to link with young people in the UK and abroad, to understand more about passports for use by specific patient groups, as compared to passports that are designed to be universal. In 2013-2014, they will be carrying out a research workstream to answer their defined questions. There is a lack of published evidence about the different approaches to designing and using health passports and so 'UP' hope to make a useful contribution to this field.

Protocol of a Transition Study from Canada

Of particular interest to clinicians and researchers may be the recent publication of the LETS Study Protocol. Transition Researcher Hannah Merrick outlines the approach taken by the Canadian research, offering comparisons with our own research.

Longitudinal Evaluation of Transition Services ("LETS Study"): Protocol for outcome evaluation. Tsybina et al., 2012. *BMC Pediatrics*

http://www.biomedcentral.com/1471-2431/12/51

Tsybina et al. (2012) published their study protocol (LETS) describing a prospective, longitudinal, mixed-method evaluation of the LIFEspan ("Living Independently and Fully Engaged") model.

LIFEspan is a two-year transition preparation model for adolescents with childhood-onset disabilities, offering help to co-ordinate their transfer of care through a formal linkage and cross-appointed healthcare providers.

They describe a 'process evaluation', which will detail the specific service delivery that occurs using a chart audit tool and qualitative interviews; and an 'outcome' evaluation that will measure the effect of the model on: 1) continuity of care; and 2) secondary outcomes related to health, wellbeing, social participation, transition readiness and health care utilization.

The sample includes adolescents with a diagnosis of Cerebral Palsy (CP; n=30) or Acquired Brain Injury (ABI; n=50) who receive LIFEspan. Two comparison groups will be used; a group of adolescents with Spina Bifida (n=21) for whom LIFEspan is not available and a cohort of young adults with CP (n=20) or ABI (n=15) who had been discharged prior to the formal launch of LIFEspan. Unlike our study, the evaluation also includes young people with severe intellectual impairment for whom only proxy outcome measurement can be obtained.

First baseline data will be taken at age 17 years, corresponding to the completion of year 1 of LIFEspan. The second will occur at age 18 years, prior to discharge, at the end of year 2 of LIFEspan and follow-up measurements will be taken at age 19 years, 1-year post-transfer.

The primary outcome, 'continuity of care', is a process measure rather than a health outcome, although secondary outcomes are similar to our Transition Programme's primary outcomes, albeit using different instruments. Both studies also include a qualitative component to assist interpretation of findings. LETs evaluates the specific LIFEspan intervention, which is currently only available in one paediatric centre in Canada. Their study may therefore produce less generalizable findings than ours, which is evaluating good practice components of all transitional care.

Like our programme, the LETS study hopes to begin to fill the gap in the transition literature by providing evidence of outcomes post transition to adult healthcare services. They also hope the study will provide evidence to support the use of the LIFEspan model and its adaptability to other organisations, different clinical settings and for young people with other complex health needs.