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Young People's Newsletter

Issue 3, February 2015

**Great News! The longitudinal study is going really well.
Over 90% of you have stayed involved in the study.**

We are very pleased so many of you are continuing to share your experiences of transition.

Thank you for working with us!

Inside this issue:

Updates from other parts of the Transition Programme, including:

- Great News from our Young People's Group!
- YETI Study: Update on progress
- Q-Sort Study: Our research findings and how we are using them in the research programme
- Useful Links for Young People

Great News From Our Young People's Group!

- The **great work of our young people's working group, 'UP'**, has been **recognised by the National Institute for Health Research (NIHR)**- the people who have funded the Transition Research Programme.
- 'UP' are featured on the NIHR website in an article highlighting some of the group's achievements.
- UP's latest piece of work was creating a DVD on **developmentally appropriate healthcare** called '**Transition's Got Talent**'. In the DVD members of UP use the format of well-known TV talent shows to highlight good and bad practice in relation to developmentally appropriate healthcare.
- Read the full article at; <http://www.nihr.ac.uk/newsroom/get-involved-news/young-people-lead-on-developmentally-appropriate-healthcare-dvd/2510>



Young People's Experiences of Transition:

YETI Study



CONGRATULATIONS to Rose on the birth of her little boy!

- This study is helping us get a more in-depth understanding of young people's experiences of transition.
- Some of you have met Rose Watson who has been working on this part of the programme. We have a new member of the team, Michaela Fay, who will be taking over YETI while Rose is away.
- **10 young people** from the longitudinal study (plus their nominated healthcare professional and someone close to them) have been interviewed so far.
- Michaela will now be approaching another 5 young people to take part in YETI.

Q-Sort Study



Jenni Hislop
Research Assistant

- ⇒ The Q-sort study looked at young people's views, opinions and beliefs on transition services in 2013 -2014.
- ⇒ 41 young people (who were not taking part in the 3-year study), aged 14 - 22 years with long-term conditions were recruited.
- ⇒ They were recruited from nine specialties, including; rheumatology, surgery/urology, endocrinology/diabetes and cardiology.
- ⇒ They were asked to place a series of statements about transitional care into order of importance *to them*. There were four themes around transition that emerged:

1) Valuing the social aspects of healthcare

- Opportunity to meet other young people with similar condition
- Have a key worker
- Opportunity to say 'goodbye' to staff in children's services
- Important that staff are interested in other aspects of the young people's life as well as their health
- Staff should mention teenage issues such as drugs, sexual health and smoking

2) Gaining more independence

- Reduce parents involvement in young peoples care.
- Staff should encourage young people to make their own care decisions and help to prepare them for independent living
- Meeting the adult clinic staff beforehand might make transition easier

3) Feeling laid-back about transition

- Changing doctors would "just be the same"
- Happy to have parents involved
- Happy to listen to what staff had to say but would like information to be provided in more varied ways than just listening to staff all the time

4) Feeling worried about transition

- Feeling 'attached' to staff and wanted opportunities to build up trust with new adult clinicians
- Keep parents to involved in young persons healthcare
- Service that would cater for their friends and family's needs as well
- Have a written transition plan

These findings were used to help design the new questionnaire you complete at visit 3 about your 'Preferences for transition services'.

You might be interested in Jenni's blog about a Transition Study Day she attended at London South Bank University:

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

USEFUL LINKS:

DRIVING:

Diabetes UK guide for driving with diabetes: http://www.diabetes.org.uk/Guide-to-diabetes/Living_with_diabetes/Driving/

Driving with cerebral palsy: <http://www.rica.org.uk/content/motoring-cerebral-palsy>

The National Autistic Society has several pages about getting your licence and learning to drive with ASD: <http://www.ncl.ac.uk/itservice/teaching-services/avbookings/equipmentloanservice/>



UNIVERSITY OR STARTING WORK:

Remploy have lots of tools designed to equip you with what you need to apply for and gain employment: <https://www.remploy.co.uk/en/individuals/tools/>

Youth Health talk shares some young people's experiences of managing their diabetes when going to university and starting work: <http://www.healthtalk.org/young-peoples-experiences/diabetes-type-1/university-and-work>

The National Autistic Society has information about applying for and starting university: <http://www.autism.org.uk/living-with-autism/education-and-transition/further-and-higher-education/starting-university.aspx>



Information about **Disabled Student Allowance (DSA)** for students living in England can be found via this link: www.gov.uk/disabled-students-allowances-dsas/overview



Hello,
I'm Guio!

I work as a research assistant on the TRANSITION programme in Northern Ireland. I have been visiting young people with cerebral palsy in Northern Ireland. So far I have done two years worth of visits and there are two more to go. It is definitely helping me see new parts of the country I didn't know!

I trained as a physiotherapist and have been working in research for a few years, initially with adults with multiple sclerosis and stroke and now children and young people with cerebral palsy.

I also volunteer as a swimming teacher with people with learning disabilities. When not driving around country roads I like the outdoors and a bit of crochet to wind down.

If you'd like to contact us, please do:

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