

## SNAPSHOT OF 2016 so far

The Transition Programme is now in its final year! Many of the work packages are coming to an end and are focussing on analysing the findings and disseminating results.

The Programme's largest study, the longitudinal study, completed data collection at the end of October. The young people taking part have been interviewed for the fourth (and final) time about their health services, wellbeing and quality of life. Retention remains strong at about 70%. Work on this part of the programme is now focussing on preparing and analysing the data.

The qualitative 'YETI' study, which involves 13 of the longitudinal participants sharing their experiences of transition in more detail, is completing its final interviews with adult healthcare professionals. The YETI team are currently undertaking the huge task of coding and analysing all the interviews. They have pulled out some interesting findings about the proposed beneficial features of services (such as whether young people have a written transition plan, or a key worker), which are being looked at alongside the quantitative data we have on the features as well.

In other activity, the Transition Programme has organised and attended several conferences so far this year, including the European Academy of Childhood Disability in Stockholm, where Rachel Pearse (medical student) presented our findings comparing service-reported provision with patient-reported experiences.

We were successful in receiving funding from the Health Foundation to run another external seminar on Commissioning for Transition for young people with long-term health conditions. The event was held at the Kings Fund in London in June. The focus of the day was the current challenges to commissioning for Transition and to reflect on the current state of commissioning from academic, policy and practitioner perspectives in the health and social care sectors.

We shared some insights from our own work package on commissioning and heard presentations from colleagues within the field including;

- Implications of NICE Guidelines for commissioning
- Evidence informed commissioning
- Hearing the voice of and engaging users in commissioning for people with long term conditions
- An example of bringing commissioners and providers together in the South West
- What can healthcare commissioning learn from social care?

It was a very successful day, stimulating some very interesting and informative discussions.

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### Conferences Attended:

- Professor Ann Le Couteur was invited to speak at a joint conference with the Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry and General Adult Psychiatry event in October 2016. Some of preliminary findings about mental health were presented. The conference was a great success in bringing both child and adult psychiatrists together.
- Professor Allan Colver was invited to present at two meetings in Houston, Texas in late October. The first was a one day conference on research on transition attended by about 60 people. Then there was a two day conference on educating professionals about transition attended by 300 people and streamed to 47 US hospital and university sites! So this was an excellent opportunity to disseminate the thinking behind our programme of research and some preliminary results.

### Looking Ahead....

Looking ahead to 2017, one key area of Programme activity will be analysing the data from our longitudinal study and then the focus will turn to writing the final report. Another area of focus is the work on a toolkit for professionals on providing Developmentally Appropriate Healthcare (DAH).

An evaluation of how DAH was being introduced in three NHS Trusts was completed last year. Two publications resulted and another is being written.

As we will be likely to recommend that Developmentally Appropriate Healthcare should be commissioned and that NHS Trusts should then deliver it, we are now compiling a toolkit to make it as straightforward as possible for a Trust to introduce DAH. This is being developed in conjunction with the Association of Young People's Health and should be available from about May next year.

DAH was emphasised in the 2016 NICE Guidance on Transition. It takes account of the developmental stage of a person. DAH is readily understood in relation to young children or the elderly with failing memories but is equally important for young people. DAH for young people provides bridging and continuity across adolescent, young adult and adult care. For an excellent video of DAH in action, we recommend - <http://www.youtube.com/watch?v=6EJkOYmkxmE>

Transition has an **updated website**. We hope you'll find it easier to navigate so please take a look!

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



You can also follow us on Twitter **@TransitionRes**



Update



## UP Group's 'Takeover Day Challenge' at the Department of Health, London!

Our young people working group, United Progression ('UP'), were invited to take part in the 'Takeover Day Challenge' in December 2015 at the Department of Health, Whitehall, London. This is an annual event where the Office of the Children's Commissioner sets organisations the challenge of engaging in exciting ways with children and young people to lead and co-produce pieces of work.

UP, along with other groups of young people from around the country, were invited to take over the Children's Health and Wellbeing Partnership. The partnership includes local and national government, health organisations and voluntary agencies. UP were invited to the event after being recognised for their 'Transition's Got Talent' film around developmentally appropriate healthcare. This year's event was focused on children, young people and long term care, including transitions. UP focused on developmentally appropriate healthcare and transition, they showed their film clip and presented the work they have done to date including their health passport pilot study.

The young people and professionals worked together and agreed goals for the Children's Health and Wellbeing Partnership to carry forward including:

**To have a health passport for young people with long term conditions transferable to different settings. The actions for this include disseminating UP's health passport evaluation of health passports used by some services.**

### **The 'work of involvement': Examining the process of UP's role in the Transition programme**

Dr Gail Dovey-Pearce and colleagues are carrying out research which examines the factors that influence the active involvement of young people in the programme. UP has met once a month throughout the programme and its activities have been set out in this and previous newsletters. Here is a summary of the initial findings:

- The participants are involved in formative cycles over the course of the study which relate to values, attitudes and practices around involvement. These cycles have the potential to increase aspirations and decrease the uncertainties of all involved. These processes need to be actively managed in order for the 'work of involvement' to keep moving in a positive direction.
- The detail of some of the research programme's methods have changed as a result of the engagement of young people.
- The perspectives of all the researchers, and especially the non-clinical researchers, have changed as a result of engagement with UP. These perspectives relate to the seriousness with which UP have worked, the skills UP members have in presenting their ideas through video and oral presentations, and the aspects of young people's lives that they want to help.
- Involvement is a complex social process, rather than a tick-box exercise. An improved understanding of *what* involvement achieves and also *how* it works is now needed.



There have been two new publications so far this year, one more is out for review and several others are in progress:

- Q-sort study: Views of young people with chronic conditions on transition from paediatric to adult health services. J.Hislop, H.Mason, J.R. Parr, L.Vale & A.Colver. *Journal of Adolescent Health* (2016).
- Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. A.Farre, V.Wood, J.E.McDonagh, J.R.Parr, D.Reape, & T.Rapley. *Archives of Disease in Childhood* (2016).

On the website, you can also find presentations and posters by the Programme, as well as links to our previous publications <http://research.ncl.ac.uk/transition/resources>

## Events of Interest

- **May 17th-20th 2017: 29th Annual European Academy of Childhood Disability Meeting, Amsterdam.** A preliminary workshop on Transition is being organised.  
<http://www.eacd2017.org/>
- **May 24th-26th 2017: RCPCH Annual Conference, Birmingham, UK**  
[www.rcpch.ac.uk](http://www.rcpch.ac.uk)
- **September 2017: RCPCH YPHSIG Clinical symposium, London, UK**  
[www.yphsig.org.uk](http://www.yphsig.org.uk)
- **October 27th-29th: 11th IAAH World Congress, New Delhi, India**  
[www.iaah2017congress.org](http://www.iaah2017congress.org)

## Congratulations

To Sarah Nolan, our project administrator, who has taken a secondment to Newcastle University's Institute for Ageing in a new role as an Implementation Manager. Alison Mulvenna, project secretary, has done a fantastic job taking over the Transition administrator role.

To all the research associates who contributed to the Transition Programme and have moved on to the next steps of their careers.



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