

Great News From Our Young People's Group!

The National Institute for Health Research (NIHR) has recently recognised the tremendous work of the Programme's young people's working group, 'UP'. Featuring the group on their website, the NIHR is showcasing the group's achievements and outlining their essential role in the Programme's research on transition.

The UP group was formed as part of the Programme's work package on patient and public involvement, addressing the need for research to incorporate the views and contributions of young people. The young people in the group all have experience accessing secondary health services, and have helped the Programme through activities such as:

- Presenting at the Programme's launch event;
- Assisting with the development of materials for the Q-Sort study, and designing certificates of participation for the longitudinal study;
- Conducting preliminary research into health passports, which some hospitals use to assist with the transition of young people to adult services.

NIHR has drawn particular attention to UP's latest piece of work, 'Transition's Got Talent' — a DVD on developmentally appropriate healthcare. In the DVD, UP have adopted the format of well-known TV talent shows to highlight good and bad practice in relation to DASH. This creative approach shows one of the great benefits of having a young person's group on the Programme —their ability to present research in a more fun, accessible and experimental way.

It's great to see their efforts recognised by the Programme's funding body. If you would like to see the article please visit: <http://www.nihr.ac.uk/newsroom/get-involved-news/young-people-lead-on-developmentally-appropriate-healthcare-dvd/2510>



Or, to learn more about UP see:

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



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Implementation of Developmentally Appropriate Healthcare in an Organisation. (IDAHO)

As the final round of fieldwork for the IDAHO study draws to a close, we wanted to share some of the preliminary findings from the research, specifically in relation to how the concept of Developmentally Appropriate Healthcare (DAH) is understood by academics and healthcare professionals.

What is IDAHO?

IDAHO is qualitative research, looking at healthcare professionals' understanding and experience of DAH. It also examines the barriers and facilitators to introducing DAH in NHS trusts.

Methods

There have been 3 parts to the research:

- A scoping review, which looked at 62 articles that mention the concept of DAH;
- Observations of interactions in 3 hospitals across Birmingham and North Tyneside (children's; district general; and adult tertiary);
- Interviews with 53 healthcare professionals (35 from clinical teams and 18 managers).

Findings

The scoping review found that there was no formal definition of DAH in academic literature. This is also reflected in practice, with health professionals finding it difficult to define DAH. Furthermore, there is no shared understanding of how it would look in practice.

The research found several gaps between the views of professionals and academic literature. For example, there was not recognition in academic literature that young people go through major life transitions simultaneously across different aspects of their life. However there were areas of overlap, which could bring a definition closer:

- DAH is more than a term, it's an approach;
- It sees the young person in the wider context of their life;
- It incorporates informational and educational goals;
- It is informed by development (biological, psychological, social and vocational);
- DAH requires an appropriate environment, and is delivered in a flexible and responsive service
- A young person's development should be considered during interactions with them and their parents.

More information

The scoping review mentioned above has now been published in Archives of Disease in Childhood, and can be viewed at <http://adc.bmj.com/content/early/2014/09/26/archdischild-2014-306749.abstract>



Two of the study researchers, Drs Victoria Wood and Albert Farre, have recently written a blog on DAH on the Transition Programme website: <http://research.ncl.ac.uk/transition/Blog.html#DAH>



If you would like more information on this or any of our studies, please email us for more information: transition@ncl.ac.uk



Follow us on Twitter—@TransitionRes

**This summary includes preliminary results and unpublished data, please do not use or cite without the permission of the authors*



Our Mid –Term Report

The Transition Programme is a 5-year research programme, and it seems incredible that we have already reached the midpoint in our research! We thought at this point it would be helpful to take stock of how our studies are progressing.

Progress to date:

Objective 1: *Work with young people with complex healthcare needs to determine what successful transition means to them and what is important for their transitional care.*

As part of this objective, Northumbria Healthcare Trust led on the formation of a young people's working group, UP. You will have already read what they're currently up to on the front page, but you can also get a glimpse of their monthly meetings on Twitter (re-tweeted by @TransitionRes)

Researchers also conducted a 'Q-Sort' study under this objective. For this, they asked 44 young people (23 women, 21 men) being seen at a variety of clinics at Newcastle upon Tyne Hospitals to rank statements on features of care in order of importance to them. These preferences are currently being probed further in the Discrete Choice Experiment (DCE), a questionnaire which asks young people to choose between models of care. This is being conducted at visit 3 of the longitudinal study, enabling a much larger cohort of young people to express their views on which aspects of care are most important to them.

Objective 2: *To identify the features of transitional care that are effective and efficient*

The longitudinal study is now well underway. This is the Programme's largest study and it follows 374 young people in England and N. Ireland as they make the move from child to adult services. All of the young people were being seen in child services for i) diabetes, ii) cerebral palsy, or iii) ASD + another mental condition at the time of recruitment. Each young person is visited at 12 month intervals, where they answer a series of questionnaires on their **healthcare services**, their **health** and **wellbeing**. Between visits they also keep a log of their healthcare appointments. Nearly all young people recruited to the study have now been visited twice, and some have had three visits. We are delighted that 90% of young people who joined the study have remained on it at visit 2! The final visits will be conducted by January 2017. A published protocol for this study can be found at <http://www.ncbi.nlm.nih.gov/pubmed/23875722>

Alongside the quantitative work outlined above, there is also a qualitative study under Objective 2, which captures the young people's experiences of transition through interviews, clinic observations and the use of a diary. Ten young people from the longitudinal study (plus their nominated healthcare professional and 'significant other') have been recruited so far, with another 5 to follow.

Objective 3: *To identify, describe and understand the factors that enable or inhibit the introduction of Trust-wide developmentally appropriate health care.*

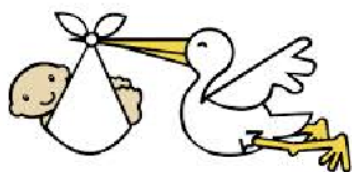
Details of the IDAHO study, looking at the implementation of developmentally appropriate healthcare at Northumbria and Birmingham Hospitals, can be found on page 2 of this newsletter. The other research under this objective is around commissioning (deciding what services should be developed and paid for by the NHS). Specifically, it is looking at the barriers and facilitators to commissioning for transition. For this, researchers have conducted interviews with representatives from primary and secondary healthcare, mental health services, care commissioning groups and the voluntary sector to examine the factors which encourage effective commissioning.

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Looking forward

There's obviously a lot of work left to do over the next two years, and we look forward to sharing the findings of our research in due course. This will include UP's research on health passports, and the results of the longitudinal study.

We are also particularly looking forward to hosting a series of events and seminars later in the Programme, so that we can engage further with fellow healthcare professionals and researchers.



CONGRATULATIONS to one of our Research Assistants, **Rose Watson**, on the birth of her little boy!

Events of Interest—2015

- **March 18- 21st — Society for Adolescent Health and Medicine Annual Meeting**
Embracing Transitions: Promoting Health Throughout Adolescence and Young Adulthood
Los Angeles
<http://www.adolescenthealth.org/Meetings/2015-Annual-Meeting.aspx>
- **April 30th—31st — Royal College of Paediatrics and Child Health Annual Conference**
Birmingham
<http://www.rcpch.ac.uk/annual-conference/annual-conference-2015>
- **May 27th- 30th—European Academy of Childhood Disability 27th Annual Meeting**
Copenhagen
<http://edu.eacd.org/node/252>
- **October 12th—Royal College of Physicians**
Transition: Developmentally Appropriate Care for Young People with Long-term Conditions
Details to follow



**Wishing you a Merry
Christmas and a
Happy New Year**



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