



## NEWSLETTER



# Happy New Year!

The Transition Team would like to wish you all the best for 2013.

### Programme Launch

The official launch of the Transition Programme took place on 26th September 2012. Held at the Great North Museum in Newcastle, the event was well attended, with representatives from:

- Children's charities
- Regional healthcare trusts
- Alder Hey Hospital
- Universities
- Families affected by transition issues.



The undoubted highlight of the launch was the **presentation by a few members of 'UP'**, the young people's working group assisting with the Transition Programme. 'UP' outlined their role, their achievements to date, and their hopes for the programme.

The launch attracted **some media coverage**, including the regional newspapers and the local news. Online BBC news coverage can still be viewed at <http://www.bbc.co.uk/news/uk-england-tyne-19703157>

The Transition Team would like to thank all those who attended the launch and made it such a success. We look forward to opportunities for collaboration in the future.

For further information on the launch, or a copy of the presentations, please contact [transition@ncl.ac.uk](mailto:transition@ncl.ac.uk)

**Transition** is a 5-year programme, examining how health services can contribute most effectively to facilitating successful transition of young people with complex health needs from childhood to adulthood.

### Spotlight on Transition Issues

#### Report of the Children and Young People's Outcomes Forum

In July 2012, the Report of the Children and Young People's Outcomes Forum was published.

This independent forum had been tasked by the Secretary for State with developing a strategy to improve the care for children and young people.

Of particular interest to the Transition Programme is the recommendation for 4 new NHS outcome indicators, two of which specifically relate to transition:

- \* effective transition from children's to adult services; and
- \* age-appropriate services – with particular reference to teenagers.

On behalf of the Transition Programme, Prof. Allan Colver contacted the Forum Chairs inviting further discussion and collaboration around these proposed new indicators.



For more information and to view the report go to <http://www.dh.gov.uk/health/2012/07/cyp-report>

For more information on Transition please view our website:

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

## Transition Programme Progress Update

The Transition Programme officially started in May 2012 and is split into 9 discrete areas of work, or 'work packages'. One of the first work packages to get underway was the development of the young people's working group, 'UP', which is introduced below. Other key areas of progress are:

## \* The Longitudinal Study

The largest work package in the programme, the longitudinal study follows young people over a period of 3 years, as they make the transition from child & young people's services to adult healthcare. These young people all have long term health conditions, with **3 exemplar conditions** being examined

- **Diabetes**
- **Autism Spectrum Disorder**
- **Cerebral Palsy**

This study is now well underway, with Research Associates in post across England and Northern Ireland. To date **96** young people have been recruited, visited and interviewed about their subjective wellbeing, participation, satisfaction with services and physical health status. They will now be revisited annually.

\* **Formation of the External Advisory Board**

Independent oversight of the Transition Programme is provided by the External Advisory Board. Composed predominantly of independent members, including the voluntary sector and families affected by transition, this board offers expert advice and challenge to the programme. The first meeting was held in October 2012.

## \* Collaboration Opportunities

At the launch and through e-mail contact, many people and groups have told us of their experiences as a young person or roles in the voluntary sector, service development or research. This newsletter is going to all those and we are developing plans for workshops and conferences over the next 5 years to share this expertise. We are also keeping abreast of international research.

# Introducing United Progression



**'UP'** is the young people's working group for the Transition Programme.

- \* It's comprised of around **20 members**, all of whom have experience of accessing secondary healthcare services.
- \* The role of 'UP' is to represent the voices of young people in the programme.
- \* Members work in partnership with the Programme Management Board, influencing decision making.
- \* It is an opportunity for young people to work alongside professionals on an equal footing.

UP's **achievements** to date include:

- Creating a strong identity through the development of their name and logo;
- Creating and delivering a presentation for the launch event;
- Designing certificates of participation for young people recruited to the 4-year longitudinal study;
- Assisting with the development of statements for use in the 'Q Sort study'.

**To contact the Transition team please call 0191 282 1389 or email [transition@ncl.ac.uk](mailto:transition@ncl.ac.uk)**

The Transition Research Programme is independent research commissioned by the National Institute for Health Research (the research arm of the NHS) under its Programme Grants for Applied Research funding.