Dear researchers

In this newsletter, we tell you about the results of the Transition Programme of research. You may remember when we asked you to get involved (about 4-5 years ago!) we asked you to be researchers, the 'ears and eyes on the ground', when you were in contact with health services.

It is a big commitment, agreeing to be part of a research project for three years. You have done a terrific job! Because of the numbers of young people and parents/carers who kept in contact with us and filled in all those questionnaires, we are able to give some strong answers to questions about what really makes a difference in how healthcare is provided. We are now talking with the people who can make changes in how services are organised. So your efforts should make a difference in the future for young people making their transition out of child services.

As the people who coordinated the Transition longitudinal study, we would like to thank you very sincerely. And wish you all the best for your future.

Helen and Allan

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TRANSITION

Young People's Newsletter

Issue 8, November 2017

Findings and Implications from the Transition Research Programme

"How can health services contribute most effectively to facilitating successful transition of young people with complex health needs from childhood to adulthood?"

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Newcastle University

Northumbria Healthcare NHS
NHS Foundation Trust

Overall Purpose:

To promote the quality of life and health of young people with long term conditions, by generating evidence to enable NHS Commissioners and Trusts to facilitate successful transition of young people from child to adult health services, thereby improving health and social outcomes.

Objectives:

1. Work with young people with long term conditions to determine what successful transition means to them and what is important in their transitional care.

2. Identify the features of transitional care that are effective and efficient.

3. Determine how transitional care should be organised, provided and commissioned.

This was a 5 year research programme. Throughout the study we have been sending you newsletters to keep you updated on how the research was progressing and to share some early results with you.

Now the study is complete, the analysis is done and we have written our final report.

We can’t share all the results with you yet but have included what we can share with you so far.

We hope you find it interesting and can see how your efforts contributed to the research.

What now?

We do not want this to be the end of our work. We really want people to take these results and implications forward to improve services for young people.

In October we held an event in London to present these findings to other researchers, healthcare providers from children’s and adult services, commissioners (the people who make decisions about services), and representatives from the Department of Health.

The day was a great success. Everyone was impressed with the research and acknowledged the importance of the findings.

All the presentations from the day are on our website if you would like to look at them.

TRANSITION

NHS
Northumbria Healthcare
NHS Foundation Trust

Making healthcare work
for young people

A toolkit to support delivery of "Developmentally Appropriate Healthcare" in the NHS

We have written a full report of all the findings which is currently being reviewed before being published. Once this is published we will be bringing all the findings to the attention of key people who can help improve services for young people e.g. commissioners, transition researchers and healthcare providers.

We will be updating our website regularly with new information so check it for updates:

www.research.ncl.ac.uk/transition

5. Developmentally Appropriate Healthcare should be provided across all NHS Provider Organisations.

“Developmentally Appropriate Healthcare’ (DAH) recognises the changing biopsychosocial developmental needs of young people, and the need to empower young people by embedding health education and health promotion in consultations.”

Key principle: A young person’s developmental stage should be the starting point for appropriate provision of services.

We have developed a toolkit to train healthcare providers in delivering developmentally appropriate healthcare.

6. We undertook a study which involved asking young people to put in order of importance statements about transition.

We found a young person usually adopted one of four approaches to transition and it would be worth discussing yours with your health team. Some young people are *pretty laid back* and relaxed about transition. Some are *anxious about transition*. Some really want *to be in control* and lead what is going on. And the final group, which overlaps a bit with the others, is called *socially oriented*. The young person really likes other people to be involved and helping, whether it is close family, friends, or all the nurses and doctors in the clinic.

7. Maximal service uptake would be achieved by a service which **encouraged parental involvement**, ensured the **same staff were seen** at each clinic, emphasised the importance of **good communication** with young people, and **encouraged young people to make decisions** about their care.

Good value for money would be offered by a service which provided: ‘Parental involvement that suited both parent and young person’, and a ‘Protocol for promotion of young people’s confidence in managing their health condition’.

Findings

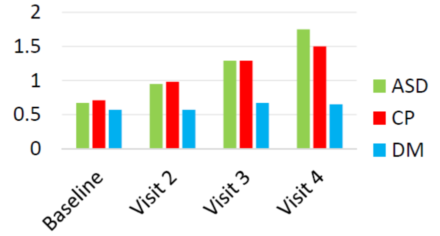
Satisfaction with Services:

Over the 3 years of the study we found satisfaction with services was reasonably good. People tended to like the current care they were receiving– particularly those with diabetes.

However, for young people with cerebral palsy and young people with ASD, their satisfaction decreased over the 3 years.

Some features improved satisfaction:

- Appropriate parental involvement
- Promotion of health self-efficacy (confidence in managing own health)



Meeting the adult team decreased satisfaction with services (possibly because it is a new service with new people to get to know).

HOW these features are provided is important e.g. the adult team member met should be seen the person the young person will be seeing in adult services.

We found the GP was not often involved in transition even though 65% of those with ASD do not transfer to an adult mental health service.

The table below shows where you all were by the end of the study:

	Total	Diabetes	Cerebral Palsy	ASD
Child services	18%	17%	14%	23%
Adult Services	66%	96%	55%	35%
GP	34%	4%	45%	65%

Remember the DCE questionnaire you did at visit 3? This is what it showed….

One size does not fit all– ideally services should be flexible to meet the needs of individuals.

Clinics that welcomed parental involvement were highly valued.

Other important features included:

- Information being passed on to the right person
- Staff offering choices and allowing people to make decisions about their care
- Seeing the same staff at each clinic
- Care was holistic (help to prepare young people for everyday life)

Implications

The findings from our research have led to 7 implications that we think would improve transition for young people with long-term health conditions.

1. Transition is not just the responsibility of those in charge of child services. Transition services should be a part of both child AND adult services. Where appropriate these services should be sourced for GP services as well.

Currently transition services are regarded as the responsibility of children services commissioners to commission and of paediatric services to provide – this is not appropriate as Transition continues to approximately age 24.

2. Child health clinicians should plan transition procedures jointly with adult clinicians and general practice.

3. Better transitional care should be the focus of all staff.

We found there were "transition champions" in organisations that worked to improve transition but when they leave their efforts are lost. We suggest organisations have a Transition Steering Committee and Coordinator to support all staff in providing better transitional care.

4. The following service features were associated with better outcomes for young people (e.g. satisfaction with services):

a. **Meeting the adult team before transfer:** It is helpful if you and your parent(s) can meet the adult team before you transfer across. This can reduce your anxieties and improve communication between the staff in the child and adult services.

b. **Promotion of young person's confidence in managing their health condition (health self-efficacy):** You should be being helped and encouraged to take responsibility for the care of your health condition. This should happen gradually and at a pace that suits you. The healthcare team should be talking about this with you regularly and asking you in what areas you feel confident or not so confident.

c. **Appropriate parent involvement:** Both adults' and children's services should give you the opportunity to talk with your doctor or nurse by yourself. However, especially in the adult service, you should say whether your parent(s) could also meet with the healthcare staff. However, if you prefer your parent(s) not to join part of the consultation hat is fine because you must feel comfortable with the arrangement if it is going to work.