



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



Northumbria Healthcare NHS Foundation Trust and Newcastle University have developed a research programme to answer this question. The Programme involves further NHS Trusts and the voluntary sector.

The Transition Research Programme ended in October 2017. Over the last year the study team have been analysing all the data and writing the final report. This has been submitted to NIHR and in due course will be published in the NIHR Publications Library.

We cannot share all the findings with you yet but have included in this briefing what is in the public domain.

The programme was closed with a meeting at the Kings Fund in London to share some of the findings and begin discussions on how the key implications could be taken forward. Jim Mackey, Chief Executive, NHS Improvement opened the meeting for us and the day was a great success. In attendance were healthcare providers from children's and adult services, commissioners, researchers and representatives from the Department of Health. Everyone was impressed with the research and acknowledged the importance of the findings.

KEY IMPLICATIONS FROM THE PROGRAMME

1. Transitional care should be commissioned by commissioners of adult services as well as by commissioners of child services.

It was found that commissioners and providers regarded Transition as the responsibility of children's services; this is inappropriate as Transition extends to approximately age 24. Where an adult service to which to transfer young people with a long term condition is not commissioned, commissioners should set out explicitly that the transfer arrangements will usually be to primary care, and require appropriate documentation and assistance to the young person to make their first appointment.

2. A framework to provide 'Developmentally Appropriate Healthcare' across NHS organisations should be commissioned, with the stipulation that this is owned at Chief Executive and Board level.

In operational terms Developmentally Appropriate Healthcare focuses on the approach of healthcare professionals to and engagement with each young person and their carers, alongside the structure of the organisations in which care takes place.'

3. NHS organisations should adopt a Trustwide approach to implementation of better transitional care. A Transition Steering Committee, chaired by a Trustwide Transition Coordinator, can facilitate this.

In many Trusts it was found that good practice led by enthusiasts rarely generalised to other specialties or to adult services. At sites we visited where there was a Transition Steering Committee, chaired by a Trustwide Transition Coordinator, this took advantage of the skills and enthusiasm of those already providing good practice; and assisted with training and consistent implementation in adult and child services and across specialties.

4. Child clinicians should plan Transition procedures jointly with the relevant named adult clinicians and general practitioners.

This is not just about the transfer of individual young people; it is also about joint planning of the services for transitional care; in other words the framework of Developmentally Appropriate Healthcare and the features of transitional care services the Research Programme found to be beneficial.

5. Child and adult healthcare providers should explore with a young person how they approach Transition and personalise the clinical approach thereafter.

We found there were four broad interaction styles that young people adopted when approaching their Transition: 'laid back', 'anxious', 'wanting autonomy', and 'socially oriented' (welcomed support from and frequent discussions with family, friends and all healthcare professionals).

6. The features 'Appropriate parent involvement', 'Promotion of young people's confidence in managing their health condition (health self-efficacy)' and 'Meeting the adult team before transfer' were associated with greater satisfaction with services, participation, subjective wellbeing and measures of disease control.

Therefore, we advise consideration should be given to ensuring that a commissioning specification includes that these features are delivered by NHS organisations.

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'.

To find out more about this research, including presentations from the day, please visit:

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