

The **National Institute for Health and Care Excellence (NICE)** is a group established by the government. They look at the evidence for new treatments and advise on broader topics such as 'obesity' or in this case 'transition from children's services'. For a topic like transition, there is little good quality evidence – but the committee still makes recommendations which then must be taken account of by the NHS.

Below is a summary of the main recommendations of the guidance (<https://www.nice.org.uk/guidance/ng43>). We have **highlighted** the areas where the Transition Research Programme is hoping to provide evidence.

Overarching Principles

1

- **Involve young people** and their carers in service design, delivery and evaluation.
- Ensure transition support is **developmentally appropriate** and transition support focuses on the strengths of the individual.
- Use person-centred approaches such as treating the young person as an equal partner in the process, agreeing goals etc.

Transition Planning:

2

- Start transition planning early (aged 13-14yrs), ensure the transition planning is **developmentally appropriate** and involves the young person - **make tools available such as written information**, communication passports, and materials for planning.
- Help the young person identify a single practitioner (a **'key worker'**) to coordinate their transition care and support.
- **Build independence**: put young people in touch with peer support groups if they want such contacts. If the young person has long-term conditions, ensure they are helped to manage their own condition.
- **Parental involvement**: ask the young person regularly how they would like their parents/carers to be involved. Discuss the transition with the young person's parents/carers to understand their expectations.

Support before and after transfer

3

- **Before**: Ensure that a practitioner from the **adult services meets the young person before they transfer** from children's services. This could be by arranging **joint appointments or running joint clinics**.
- **After**: If a young person has moved to adults' services and does not attend meetings or consultations, services should try to contact the young person and their family, and involve the GP if appropriate. If the young person still does not want to engage, the relevant provider should refer back to the **key worker** with clear guidance on re-referral or alternative ways to support them.

Supporting Infrastructure

4

- Each health organisation, in both children's and adults' services, should nominate a senior executive to be accountable for developing transition strategies and policies; and a senior manager to be accountable for implementing transition strategies and policies. The senior executive should be responsible for championing transition at a strategic level.
- Jointly plan services for all young people making a transition from children's to adults' services.
- Service managers should ensure there are **developmentally appropriate services**.

Thoughts of Professor Allan Colver (Chief Investigator), August 2016:

Overall, I am pleased that NICE have produced Guidance on Transition. It raises the profile of Transition and requires health services now to have arrangements in place.

I think the guidance is so long, with so many recommendations, that it will be daunting for the health service to implement it.

I hope that the **Transition Research Programme will provide evidence** of what works and so allow subsequent guidance to be more succinct and achievable.



Young People's Newsletter

Issue 6, October 2016



At the end of October 2016 this study will come to an end and all the final visits will be complete.

The success of the research is down to you for staying involved for the full 3 years!

We will keep you updated on our progress with analysis and send you a copy of the final report in 2017.

Inside this issue:

- Timeline of the Transition Research Programme (page 2-3)
- Our comments on the NICE Guidelines for transition (page 4)

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TRANSITION Timeline

Where it all began and what we have achieved so far...



Feb 2010: Programme Development Grant

We spent 1 year developing the idea for the Transition research programme.

Our research found there were no models of transition for young people on the autism spectrum and very few for young people with cerebral palsy.



June 2012: All research assistants met for the first time in Newcastle for two days of training about the research and working with young people.



Nov 2013: Recruitment finished

374 young people and their parents from all over the UK joined the study to share their experience of transition.

Dec 2014: Transition Study Day

Two researchers from the team presented about the programme at a study day in London. Other researchers and health professionals interested in transition attended the day.



July 2015: Final Training Day for research assistants

The researchers came together in Newcastle for a final training day.

Oct 2015: Transition Workshop

With the Council for Disabled Children and UP group we held a workshop for young people to share their experiences of transition.

Nov 2015: End of Year 3

305 young people completed visit 3.

Sept 2011: Received funding to start the 5-year Transition Research Programme.

July 2012: First participant was recruited.

May 2012: Transition Research Programme officially began.

Sept 2012: Transition Programme Launch Event

Representatives from children's charities, regional healthcare trusts, universities and families affected by transition issues attended the event.

A highlight was a presentation by our young people's working group, UP.

Nov 2014: End of Year 2

320 young people completed visit 2.



Oct 2015: Royal College of Physicians Conference: Developmentally appropriate healthcare.

Some of the Transition Team attended this conference to present preliminary findings. We also gave a workshop on how research can support and improve transition.

Feb 2016: New NICE Guidelines for transition were published

Senior members of the research programme commented on drafts of the guidelines (see page 4).

2012: UP Group first meeting

Group made up of young people with complex health needs and peer support workers.



All the final visits will be completed by October 2016.

We will be spending the rest of 2016 analysing all the data you have given us and writing up the final report.