London South Bank University

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Centre For Outcomes And Experience Research In Children's Health, Illness And Disability

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Transition
UNDERSTANDING IT AND MAKING IT WORK

Transition: understanding it and making it work

Executive Summary

Research Team

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Burdett Trust for Nursing

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The research team would like to thank the following groups who have been involved in developing these benchmarks:

- young people
- parents
- professionals working at: Guy's and St Thomas' NHS Foundation Trust, Great Ormond Street Hospital for Children NHS Foundation Trust, Chelsea and Westminster Hospital NHS Foundation Trust and University College London Hospitals NHS Foundation Trust.

and

- the stakeholders from various professional roles within health and social care including: medical consultants, registrars, clinical nurse specialists, psychologists, occupational therapists and academic researchers.

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Background

The journey through adolescence to adulthood is a challenging time of physical, psychological and social change. Young people with a long-term health condition face even greater challenges having also to deal with important changes in the care they need and the way it is provided. The role of the young person, and also their parents/carers, will change with the young person often wanting and being expected to exercise greater independence in the management of their condition. Health service provision which fails to meet the needs of young people and families at this time of significant change may result in deterioration in health or disengagement with services which can have negative long-term consequences. Thus, the transfer of adolescents from child to adult services is a crucial time in the health of young people who may potentially fall into a poorly managed ‘care gap’.

Transition services aim to bridge this ‘gap’ between child and adult services. ‘Transition’ has been defined as “a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from the child-focused to the adult-focused health care system” (Blum et al, 1993 p.573). Unfortunately, transition by this definition is often not always how young people describe their experience. A review by Fegran et al (2014) described themes relating to experiences of loss of relationships with the child care team combined with insecurity and a feeling of being unprepared for what was ahead. Lack of ‘being prepared’ was also a finding from the recent report on transition from the Care Quality Commission (CQC, 2014). Here only 54% of young people described preparation for transition that enabled them to be involved in the process as much as they wanted to be and 80% of pre-transition case notes reviewed had no transition plans for health (CQC, 2014). There are examples of services where successful transitional care programmes have been implemented (see Crowley et al, 2011) and the CQC (2014) reported that what works well was often associated with specialist services, such as cystic fibrosis and cardiac services, and in essence this consisted of: having consistent staff members who know about the conditions and young person’s history, good communication and good information about what to expect.

The purpose of this study was to develop an increased understanding of transition, from multiple perspectives, and to describe what strategies and resources might be required to facilitate transition with the aim of developing a benchmark tool.

Aims

1. To explore young people’s and parents’ views on how best to achieve continuity during transition from child to adult services.
2. To explore the views of health care professionals working with a range of childhood long term health conditions on how best transition can be introduced and sustained.
3. To detail a range of transitional models that best describe approaches to finding solutions to organisational barriers.
4. To describe and inform client focused best practice that will facilitate the transition of young people from child to adult services.
5. To develop and nationally disseminate a clinical practice benchmarking tool to support the structured comparison and sharing of good practice in the transition of young people from child to adult services.

Methods

This study had three phases:

Phase 1 – Data collection
This was a qualitative study. Workshops, focus groups and interviews were held with:

- Stakeholders from across the United Kingdom, leading on transition for young people from child to adult health care
- Health professionals working with young people locally in the London area at the four study sites (from both child and adult services)
- Young people aged 13 to 21 years old with a long-term health condition and their parents. Young people were recruited from the four study sites and through charities via newsletters and social media.

The groups/interviews focused on: experiences of transition, barriers and facilitators to transition. Additionally, the young people and parents were asked to develop a list of their 'top 10 essential elements of transition'.

A literature review was also planned for this phase; the team were able to join an existing Cochrane review.

Phase 2 - Benchmark development
Two researchers analysed the transcripts and information gathered from these groups and using qualitative content analysis (Morgan, 1993) extracted a list of factors that were mentioned as being important when young people move from child to adult health care, along with some examples of good care/practice in each area. This list of factors was sent out to young people and parents for them to select the factors they thought should be included in the benchmark. They were also asked to add any additional factors that had been missed along with more examples of good care/practice in each area. The benchmarks were refined following the comments from young people and parents and then sent out to the same group of young people and parents again to add in statements of best and poor care/practice for each of the factors. The benchmarks were sent out to all the stakeholders, professionals, young people and parents involved in the study so far for comment and were refined based on the feedback received. This refined document was finally distributed to the professionals, stakeholders and families for final comment.

Phase 3 – Dissemination
The final phase involves sharing our findings through publications, presentations and the study website.

Findings

Twenty stakeholders attended the groups, from various professional roles within health care and social care. The stakeholders had expertise in working with young people with many different health conditions and disabilities. One telephone interview was carried out with a stakeholder who was unable to attend any of the focus group meeting dates. The stakeholders spoke about how, '*things have become stuck'* and how changes need to be made in order to improve transition. These changes included *'changing the mind-set'* of professionals through training about adolescence and the needs of young people, more *'joined up thinking'* across child and adult services and breaking down organisational barriers.

A focus group was held at each of the four study sites which were attended by 36 health professionals (from both child and adult services). The professionals discussed the barriers to implementing transition services but also about how some of these had been overcome. Examples of initiatives to improve transition were shared such as holding transition days for families, joint clinics and development of documentation for transition. It was evident that there was little sharing of these strategies as professionals working within the same Trusts were unaware of what colleagues from different specialities had implemented.

Two workshops were held which were attended by nine young people and nine parents. Two more workshops were planned but had to be cancelled due to poor recruitment and young people being unable to attend (mainly due to being unwell or having other commitments). Interviews were offered to young people and parents who were unable to attend a workshop; four young people and two parents took part in interviews. Young people said, *'preparation is key'*; they wanted early information about transition, help to gradually take over the management of their health condition from their parents and recognition that everyone is different. Young people wanted to be treated *'like a teenager'* – not a child, not an adult, this involved: having letters addressed to them, professionals speaking directly to them and explaining things in a way they could understand and being listened to. Parents raised concerns about their son/daughter moving on to adult services:

"You want to know what to expect, what will be so different compared to what you were used to".

"I believe that once you're in adult care, you're just a number, you know, it's a totally different care"

"As a Mum it's absolutely terrifying to have to let go and to trust that X understands her conditions so well that I don't have to worry…"

Like young people, parents said what would help them was good communication and information about transition and having a clear plan.

Benchmarks for transition

For young people and their parents/carers to experience timely and effective transition eight factors and their associated indicators of best practice statements have been developed from the data (Table 1).

Table 1: Benchmarks for transition - factors and statements of best practice

Factor	Best practice
Factor 1: Moving to manage a health condition as an adult.	Young people are offered advice and information in a clear and concise manner about how to manage their health condition as an adult.
Factor 2: Support for gradual transition.	The young person as they progress through the transition process is gradually prepared and provided with personally understandable information and support.
Factor 3: Co-ordinated child and adult teams.	The young person is supported through a smooth transition by knowledgeable and coordinated child and adult teams.
Factor 4: Services 'young people friendly'.	Young people are provided with care and in an environment that recognises and respects that they are a 'young person', not a child or adult.
Factor 5: Written documentation.	Concise, consistent and clear written document containing all relevant information about the young person's transition is provided to the teams involved in the transition process.
Factor 6: Parents.	Parents are included in the transition process gradually transferring responsibility for health to the young person.
Factor 7: Assessment of 'readiness'.	The young person's readiness for transition to adult care is assessed.
Factor 8: Involvement of the GP.	The young person's GP is informed of the plan for transition and is able to liaise with other relevant teams to facilitate services requested/needed by the young person.

For further details of the benchmarks please see our benchmarking document, 'Benchmarks for transition from child to adult health services' available on www.transitionstudy.co.uk

Conclusion

The need for change, in order to best meet the needs of young people, and parents during transition is very evident. There are some excellent examples of initiatives to improve transition and how barriers to putting these into place have been overcome. These initiatives need to be shared within and between Trusts. The benchmarks for transition indicate young peoples and parents' needs and preferences regarding transition to adult care. As such they offer an example of a practice guide to support transition and could facilitate the sharing of good practice.

Dissemination achieved and planned

Conference presentations:

Aldiss S, Rose L, McCutcheon D, Cass H, Ellis J, and Gibson F. Moving from child to adult health care: Benchmarks for transition. Oral presentation at the 2014 Association of Chief Children's Nurses Conference, Jersey.

Aldiss S, Rose L, McCutcheon D, Cass H, Ellis J, and Gibson F. 'Things have become stuck': views of stakeholders about the transition from child to adult health care. Oral presentation at the 2014 International Nursing Research Conference, Glasgow.

Posters:

Aldiss S, Rose L, Cass H, Ellis J, and Gibson F. Moving from child to adult health care: Development of benchmarks for transition. Poster accepted for the 2015 joint Royal College of Paediatrics and Child Health/Children and Royal College of Nursing Young People's Nursing Conference, Birmingham.

Publications:

Gibson F, Aldiss S, Cass H, Ellis J, Pettigrew T and Rose L. Benchmarks for transition from child to adult health services available from www.transitionstudy.co.uk

Campbell F, O'Neill PM, While A, McDonagh J, Biggs K, Aldiss S, and Gibson F. Interventions to improve transition of care for adolescents from paediatric services to adult health services. This Cochrane review will be published in two parts with the first part focusing upon quantitative data relating to interventions for transition and the second on qualitative research on young people's experiences of transition.

Four journal papers are in progress, focusing upon:

1) Stakeholders views of transition – Journal of Child Health Care.
2) Local professionals' views and experiences of implementing transition – Archives of Disease in Childhood.
3) Development of the benchmarks for transition – Journal of Pediatric Nursing special edition on transition.
4) Commentary paper about transition – RCN Nursing Children and Young People.

Transition Study Day:

As part of our dissemination, we held a one day conference on transition at London South Bank University on 5th December. The aim of this day was to bring together people working on transition across the country, enable people to share their work and to present the benchmarks for transition. The day was attended by around 135 professionals from across the UK. Feedback from this event was very positive with attendees reporting that they found the day good for networking and gave them ideas about how to improve transition for the young people they work with. An article from the day featured in the February issue of the RCN journal, 'Nursing Children and Young People': Newton Snow T. (2015) Preparing young people for adult services. Nursing Children and Young People, 2015, 27(1): 6.

Next steps

The professionals attending the study day and all those who took part in the study will be invited to work with us to test the benchmarks, to use them to evaluate their services and feedback on how the benchmarks work in practice. Following this period the benchmark document will be available to anyone who wants to use it, from the UK or elsewhere.

References

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