# Case Study: Developing Acute Health Pathways for Young People in Transition to Adult Services

## Introduction

**A health pathway that supports transition for young people with a range of health needs.**

## Overview

Ensuring young people with health support needs have a positive transition can be a challenge. Often a consultant pediatrician or specialist has spent many years developing both a relationship and a good understanding of a young person's health needs and this can fall apart when a young person moves into adult services.

This case study looks at a generic health pathway that has been developed to support the transition of young people with health needs in Bristol, North Somerset and South Gloucestershire.

## Main transferable learning points

- Dedicated time for professionals to talk to young people about their health needs is crucial to a positive transition
- Transition provides an opportunity to involve young people in their health care and to support them to understand the implications of any medical conditions they may have
- Supporting Commissioners to understand the "You're Welcome" standards can a have positive outcome for young people.
- Providing a yearly opportunity for professionals to come together meant the health pathway could be reviewed and embedded.

## Introduction

This case study describes the approach taken in Bristol, North Somerset and South Gloucestershire to develop and improve transition planning for young people receiving secondary acute health care services. The work took place between December 2008 and March 2010.

## Aims and Objectives

The aims of the project were to:

- identify a process to improve transition planning and support for young people receiving secondary acute health care services within the Bristol, North Somerset and South Gloucestershire provider network, building on an initial scoping project
- develop a generic transition health pathway capable of adaptation for specialisms, along with a self assessment framework to assess progress, and clear guidelines for use.
- ensure transition planning and support processes were kept under review and developed in a way that would be sustainable into the future.

## Approach

Work was led by the Transition Workstream group of the Bristol Children and Young People's Service Development Group. The following activities were undertaken:

© NCB 2011

1. The workstream group first developed an initial health pathway based on members' experience of supporting young people through transition and consultation with young people and healthcare staff, as well as local and national research on best practice and Department of Health guidance. Alongside the pathway, a draft self assessment framework and operational guidelines were also developed.

2. A young people's event, 'Moving on Up', was held, at which a group of young people using paediatric services were consulted about the transition support they would like and how they expected health care teams to support them.

3. The information and feedback generated from this event was used to amend the initial pathway and documentation in preparation for a healthcare staff consultation event.

4. At the event staff from secondary care specialities from both the paediatric and adult teams were consulted with. The teams were asked to complete the transition self assessment framework to capture the way things worked currently in their own medical specialty.

5. Representatives attended from a range of paediatric and adult specialities, including Respiratory, Rheumatology, Diabetes, Renal, Cardiac, Oncology, Neurology and Gastroenterology.

The programme for the day covered:

- Presentations were made from the Paediatric/Adult Renal Teams and the Paediatric/ Adult Cystic Fibrosis Teams, who were already had substantial experience of supporting young people through transition
- Feedback from young people who attended the Moving on Up event including excerpts from the video diary recorded at the event
- A consultation session on the draft pathway, self assessment framework and operational guidelines in mixed groups facilitated by members of the Transition Workstream Group
- A rapid improvement exercise using a "Review, Agree, Implement, Demonstrate" (RAID) based model. Each condition specific speciality team worked together on an area they had identified as in need of improvement on their self assessment framework, agreed a change that they would achieve within six months and outlined an initial action plan to deliver that change.

6. Following this event, the draft pathway, self assessment framework and operational guidelines were again revised, and shared with a wide range of groups and stakeholders, including a South Gloucestershire and Bristol Voluntary sector transition event held by the Care Forum, a regional palliative care meeting, a regional endocrinology meeting, the South West region Transition Support Programme advisors, the South Gloucestershire multi agency Transition strategy group, and the Bristol Strategic Transitions Board.

7. As a result, further changes were made to the pathway, assessment framework and operational guidelines.

## Challenges and Successes

The key challenges of this approach have been:

- Enabling and sustaining engagement from staff in adult receiving teams
- Sustaining the initial changes and commitment to improvement made at the event when there has been no ongoing support for the teams

The outcome of the process has been a generic transition pathway (see Appendix 1), self assessment framework and template for operational guidelines has been developed with wide consultation and service user involvement. The self assessment framework enables all acute specialities to complete baseline and review assessments of progress.

An interface between acute health care focused

work and the transition developments being led through multi-agency strategy groups in Bristol and South Gloucestershire has been established, with the opportunity to further integrate this work, avoid duplication and co-ordinate services for young people and their carers

Service improvements have been delivered by some of the teams attending the consultation and rapid improvement day.

Recommendations have been made that:

- Commissioners identify the elements to be integrated in future service specifications and assessment of achievement against 'You're Welcome' standards
- Provider organisations agree a process to implement the pathway approach
- SDG members identify a process to support continued service improvement in transition for young people with long term medical conditions, and fund:
    - at least two young people's events a year providing generic information, peer support and involvement in improving their experience of transition in paediatric and adult health care services
    - an annual service improvement event, enabling staff to have supported, protected and focused time to address the transition needs of the young people they see.
- Most importantly, for young people, there is now a generic approach to acute health transition that can be tailored to those with particular medical conditions.

One of the most successful elements of the process was the facilitated day which gave protected and focused time for staff to work on transition. Many commented that this had been a unique opportunity to spend time with colleagues across paediatric and adult services to develop pathways and processes together.

It seems that facilitating this intensive day enabled a deeper engagement with transition issues and faster progress than regular meetings over a long period.

Engagement with young people is also regarded as a success, particularly the transfer of their views into the rapid improvement event. Although not quite co-design, their involvement was a step beyond consultation towards genuine involvement of young people in the design of the pathways and processes that determine their experience of transitioning from paediatric to adult healthcare services.

## Conclusion

As a result of this project, the pathway and self assessment framework are available to commissioners to use as part of their specifications for services and may provide useful indicators of quality in the future. In some areas specific improvement is being further developed and the assessment framework is being used as an audit tool to support this.

The resources and information developed by young people and staff who participated in the project continue to be available when and if services want to further develop their transition processes and pathways . Some members of the original workstream group continue to take every opportunity in their provider organisations to further improve transition pathways.

In addition, initial action plans agreed at the rapid improvement event have specifically contributed to the following :

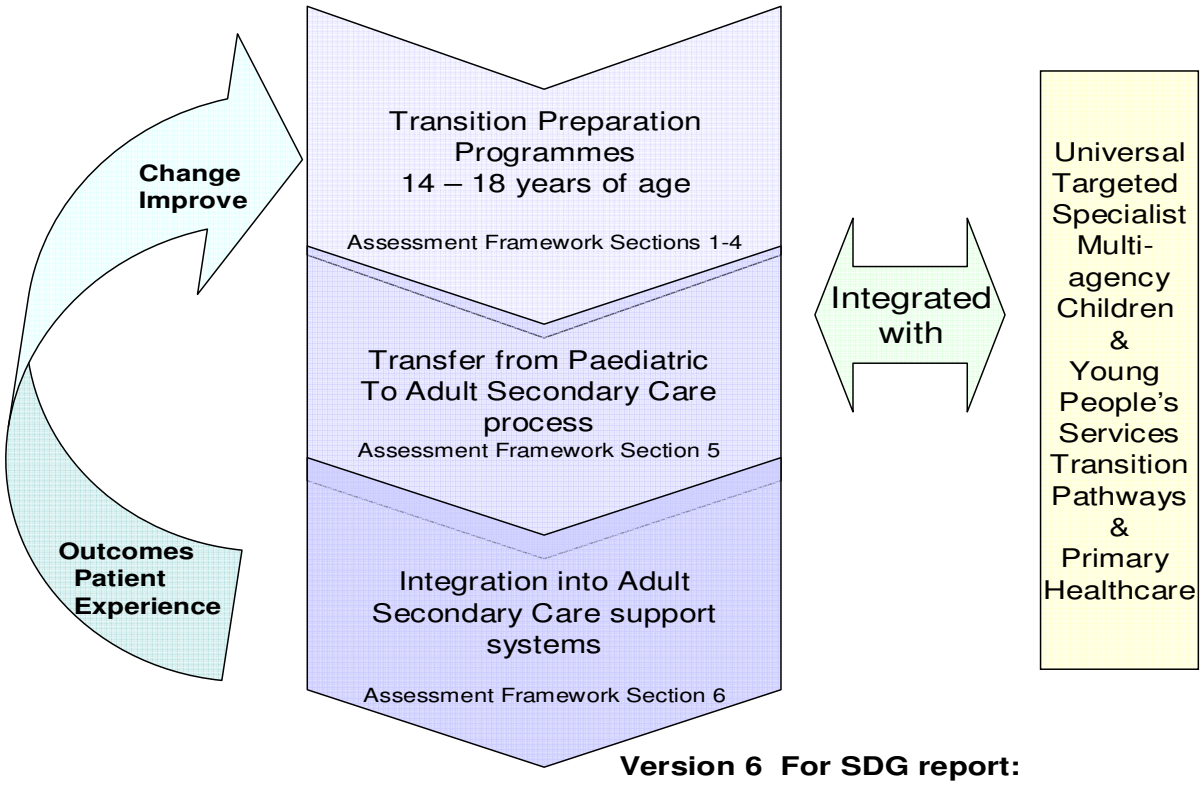
- development of a transition clinic in cardiology
- the setting up of young people's evenings in diabetes and gastroenterology
- an awareness raising campaign in oncology
- a successful bid to establish a project to improve support for young adults in renal

services.

**For further information please contact:**

Sue Dolby
Consultant Clinical Psychologist
Sue.Dolby@UHBristol.nhs.uk

**Generic Transition Pathway Integrated with the Self Assessment Framework.**




**Version 6 For SDG report:**
**GENERIC TRANSITION PATHWAY PAEDITRIC - ADULT SECONDARY HEALTHCARE**

## Acknowledgements

The National Transition Support Team would like to thank everyone who was involved with this case study.

## National Transition Support Team (NTST)

NTST is working alongside the National Strategies and the Child Health and Maternity Partnership to coordinate the delivery of the Transition Support Programme.

NTST is based at the Council for Disabled Children (CDC), the umbrella body for the disabled children's sector in England. CDC is hosted by NCB. www.ncb.org.uk/cdc

National Transition Support Team
Information line: 020 7843 6348
Email: tsp@ncb.org.uk
www.transitionsupportprogramme.org.uk

© NCB 2011