How to Use Guide for developing a transition policy for children and young people with diabetes.

The following documents have been developed by a sub-group of the North West Paediatric Diabetes Network. The aim of the work of the sub-group was to develop a “suite of tools” that would support the transition work of units providing care for children and young people with diabetes. The documents are developed as templates for people to customise to suit their local setting and services. The documents included in the suite of tools are:

- Transition Best Practice Guidance
- Paediatric and Adolescent Diabetes Transition Policy
- Individual Transition Plan
- A How to use Guide

This suite of tools and documents has been designed to help units prepare a transition policy in a structured and organised way.

Notes on their use:

The elements marked in **blue and bold** are for units to adapt for their own services and Trust. Please feel free to add your own logos and descriptions of services.

The suite of tools will be shared nationally.

We have shown also included some worked examples. These are:

- a case study for using the transition checklist
- a worked example of the transition plan

These documents have been updated as a result of comments from people as they put them into practice. If you have any further comments please get in touch.

*Ruth Gordon,*

Ruth Gordon,
North West Paediatric Co-ordinator

[ruth@ruthgordonassociates.co.uk](mailto:ruth@ruthgordonassociates.co.uk).
Case Study – Critical Analysis and Self Assessment Tool for Transition Arrangements in Diabetes Service (RMCH)

Completed by: Sue Greenhalgh

Evaluation of Transition Checklist.

The aim of the transition toolkit is to provide a self assessment tool for the transition process provided by individual services. The checklist is divided into 5 parts:

- The Team
- The individual
- Families and Carers
- Multi-disciplinary
- Monitoring.

This enables the transition process to be evaluated in each part and areas for development identified and prioritised. Prior to using the checklist the current service provision was reviewed and is identified below. This gave a base line on which to use the checklist and identify areas for development.

Background to Diabetes Service

The paediatric and young person’s diabetes team (YPDT) recognise that preparing young people for transition from a paediatric to an adult health care setting plays a vital part a successful outcome. There is significant collaboration between three Trusts to meet the needs of young people with diabetes, most significantly the development of a young person’s diabetes service providing continuity of care for young people with diabetes after the transition from RMCH.

Transition begins for young people with diabetes when they enter the Teenage Diabetes Clinic around the age of 13 years old. This clinic is run jointly by the YPDT and paediatric team. The Paediatric Diabetes Specialist Nurse (PDSN) is part of both teams contributing to smooth transition and ensuring continuity of care for young people.

Objectives for transition were based on the Diabetes NSF (2001) and aimed to ensure that the special needs young people with diabetes are recognised and met, ensuring that when they enter adulthood they are in the best of health and able to manage their own day to day diabetes care effectively. In addition standard 6 of the NSF highlighted the importance of smooth transition from paediatrics’ to adults via a young person’s clinic and stressed the importance of developing partnerships with individuals.

These aims were met by developing pathways of care for young people which ensured smooth transition and recognising that young people are a vulnerable group who are undergoing many transitions during this period of their lives who may be confused and disillusioned with an adult system and need a service which continues to meet their needs into young adulthood.
The transition service for young people with diabetes has been in place since 1987, however over the years the service has continue to develop and its success is due to the collaboration between the paediatric and YPDT. The consultant, nurse and dietician from the YPDT attend the Teenage clinic at RMCH and get to know young people many years before they move on. Young people are also given a leaflet prepared by the team called “Moving On” which highlights what to expect from the transition process. There is no age policy for transition but this normally occurs between 16-18 years and the final decision rest with the young person who is involved in all decision relating to their care. The team recognises the impact that moving on has on parents as well as young people and they are also prepared for the transition. Service users were involved in developing the pathway of care to the young person’s service and this includes gateways through which young people may move in and out of the service such as during pregnancy. Improving links with adult colleagues has lead to the development of the Young Persons Service and has improved the level of care which young people aged 16-25 receive. A survey of young people who have experienced transition to the young person’s service indicated they felt the transition worked well.

**Self Assessment**

**The Team**

Using this part of the checklist it was clear that although the team considered they had an effective transition process and a documented pathway there was no written policy in place. This had a significant impact on assessing the pathway and moved areas which should have been green to amber. Positively all the team was aware of the process and the aims of transition but again lack of documentation highlighting these aims was absent. The team also felt that whilst they had not been trained in methods of transition they had looked at other models of transition and had developed the pathway to meet the needs of individuals in the diabetes service. It was suggested that the term models of transition was used and that there should be an opportunity to attend a study day on models of transition which would enable comparison with other models to aid service development.

In relation to cross checking other pathways this was viewed that when developing the pathway consideration had been given to young people who may have another condition and may be on another pathway. Whilst the written pathway had identified gateways which young people my move this focused on areas such as pregnancy, moving to University but was not specific about young people with other conditions. A further problem when cross checking with other pathways was that other services did not have a written policy.

In part 5 again the team felt that they had considered the points identified but this was not clear without adequate documentation to highlight this. The team also felt that it should be made clear how these points are given consideration. The main problem with the lack of documentation was that it would be difficult for a new member of the team to be clear about the policy and aims of the pathway.

**Overall rating: Amber**
Areas for development.

- To write a transition policy which clearly identifies the aims of transition based on current practice.
- To include in transition pathway cross checking with other pathways in young people with another condition.
- Identify how the team gives consideration to points in part 5 and how this can be assessed in practice.

Target date:

The Individual.

This was an area which scored well mainly because the leaflet “Moving On” fulfilled many of the points in this section. The leaflet addressed points 7, 8, 9 and 11 and scored green. The team felt that each young person is treated as an individual and the transition plan is specific to their needs and that the young person is aware of it. However again there was lack of documentation specific to the individual which specified their personal transition plan. It was clear that lack of documentation meant that it was not clear that the young person had been involved in the process and had contributed to it to personalise the transition plan.

Overall rating: Amber to Green

Areas for development

- To develop a written individual transition policy which highlights that the young person has been involved in the process.
- To include in the documentation the need to address consent issues and child protection where appropriate.

Target Date:

Families and carers

Generally this was an area which scored well. The advantage of having the paediatric DSN as part of the young persons team and therefore having a long term involvement in transition meant that families had already been given most of this information. However although families had contact details of all the team involved in transition when the young person received the “Moving On” leaflet it could be made clearer to parents that the transition process had started and that they would continue to be involved. Whilst this information is often given verbally it would be of benefit produce a leaflet for parent to help them with the process.

Overall rating: Green to Amber.

Area for development:

- To develop a “Moving On” leaflet aimed at parents.
**Multi-Disciplinary**

The team scored well in this area. Members work collaboratively across trust and Children and Adult services. Consideration is given to external agencies’ such as school and social services, youth services where appropriate as part of the individual transition plan and external agencies are made aware of the transition plan. This is particularly relevant in young people with social difficulties who may not attend clinic and other agencies are made aware of the shift in service from a family centred paediatric service to an adult orientated health care system.

**Overall rating: Green**

**Area for development.**

- To maintain and sustain current level of service and to review regularly.

**Monitoring**

This was an area where the team scored poorly. Whilst there is annual report on the young persons clinic it focuses on HbA1c results, DNA’s, and numbers of young people who have been seen by the team. There has only been one survey on patient satisfaction and an audit tool needs to be developed to evaluate the transition process.

**Overall rating: Red**

**Area for development.**

- To develop an audit tool to analyse and evaluate the transition process.

**Evaluation.**

The checklist was very useful in highlighting areas which the team considered they were achieving but in fact were not. The two main themes were lack of documentation which identified and recorded that the pathway was followed and the lack of an audit tool to monitor the process.

Although the monitoring section was the only one which scored red and needed action this could not be done without clear documentation to audit. The team decided to prioritise and write the transition policy first followed by improving documentation for young people which highlighted their involvement and contribution to the process. Following this the team would develop further information for parents before moving on to an audit tool.

Target date can be set and the checklist re visited following those dates to re-assess the pathway.
Notes on how to use the transition plan and a worked example

How to use the tool:

The front two sheets are patient held.

Pages 3 – 7 are held by both the professional and the patient and can be added to as the young person works through the process. They provide a checklist of all the things the professional needs to ensure they have covered as they work through the transition process and approximate times when it will be appropriate to cover each section. The clearly needs to be adapted to suit the needs and capabilities of the young Peron and take into account how they are progressing with the transition process.

The notes would also have greater expansion on the patient notes – these pages are as a reminder for both professional and young person of what has been discussed and agreed.
Transition Plan: Example

Name: John Smith  DOB 1/2/1998

Hospital number_____________________

Transition Plan implemented by: (this is the person who first introduced transition)

Key Contact for process: (person who starts the plan is the key worker and takes responsibility for ensuring staff update the plan)

Background: Any issues that need to be considered for this patient that may affect the transition process, family issues, medical issues, personal issues etc.

Core Considerations: Service specific. E.g. If the patient lives outside the local area will they be transferred to a different adult service or move to YPT.

Additional information.

Transition pathway: This must be specific to the young person and highlight how the transition will take place. It is to be used in conjunction with the transition planning and transition checklist documents.

Short Term:
Initial discussion around transition took place on 4/1/2010. Early stage transition was discussed with John and his parent’s information given on the transition process. Relevant aspects of transition checklist completed and action plan developed. John will move from the paediatric clinic to the teenage clinic.

Medium Term:
John now attends the teenage clinic and middle stage transition plan is in process.

John and his family feel that transition process is going well.

Or
Whilst John is happy to be seen part of the time on his own at the clinic his mother feels he does not give the full story of the current management of his diabetes and she would prefer to remain in the consultation with him. Action plan developed in agreement with John and his mother to facilitate his move to independence.

Long Term:

John will be starting university in September and will move to the Young Persons Clinic in the summer.

Timescale: Starting date and potential date for final move to YPC.

Methods of feedback: John and his parents will complete transition feedback forms at medium and long term transition stage and 6 months after transfer to YPC.
Transition Feedback Form: (to be completed in discussion with young person and family)

Name ____________________________ DOB__________________

Undertaken by_______________________

Start Date_________________________

Summary of transition pathway to date:

John began his pathway in January 2008 from the paediatric clinic to the teenage clinic with a long term view of moving to the Young Persons Service. His final decision to move to the Young Persons Service will depend on whether he leaves school and gets a job or moves on to university.

The pathway was considered and planned in collaboration with John and his parents and both paediatric and adult staff.

Overall John and his family thought the transition pathway was………..

Key issues raised:

Key issues raised for John’s transition were that he was ……………………..

John and his family saw the key issues as being…………………………

These issues will affect future transition planning in that we will now aim to………………………………………………..

Refer to current action plan.

With thanks to the sub group:
- Jane Edmunds at Alder Hey (Chair)
- Sarah Ghezaieal at Stockport
- Sue Greenhalgh at Salford

| And Julie Cropper and Lyneen Finnigan for their comments on an early draft |