

national transition support team

working together to improve transition
for disabled young people

Case Study: The Young People's Transition Task Group

Introduction

A multi agency transition planning group that meet on a regular basis to support operational and strategic transition planning.

Overview

This case study looks at how Sheffield set up a multi-agency transition task group to improve the sharing of information across professionals in order to ensure positive transition planning for disabled young people. The task group looks at planning for all disabled young people with either a learning or physical disability, who are likely to require care and support from adult services.

Main transferable learning points

- Multi-agency transition planning is most successful when there is clear leadership and good communication amongst all stakeholders
- Sheffield found that having a key professional in each sector supported more positive multi-agency working
- Shared responsibility and ownership leads to staff being more positive about transition
- Providing opportunities for professionals to learn about transition and hear from young people and their families supports positive multi-agency planning

Introduction

Sheffield Teaching Hospitals NHS Foundation Trust is a 2000-bed organisation based on 5 sites serving the people of Sheffield and beyond. For purposes of clinical leadership and management, the Trust is organised into 8 Care Groups. There are 50,000 episodes of care of Children and Young People in the Trust, 45,000 outpatient and 5,000 inpatient/day case for young people aged under 18 years. This includes a number of young people with complex health needs and learning disability.

A transition task group was set up in March 2009. The remit of the task group was to oversee implementation of the Transition Guidance for all young people, including those with a learning or physical disability, transferring their care to adult services in the Sheffield Teaching Hospitals NHS Foundation Trust (STHFT).

Background

The Transition Task group STH was set up following a trust wide audit, completed in [March 2009](#), transition was one of the areas of practice that needed further work and development; The audit was also a driver to set up the post of Lead Nurse for Children & Young People. (assistant director level post) Established by the Lead Nurse, the group was formed using contacts from existing individual groups and utilising trust leads to identify the appropriate professionals and ensure they were at an appropriate level to allow freedom to act.

Lead Nurses in the 7 Care groups represent the specialities with an Advanced Health Practitioner for Therapy services; senior members of the Patient Partnership Dept, plus 2 Consultants -Renal/Rheumatology with a special interest in developing transition. Colleagues from Sheffield Children's Hospital (SCH), Consultant paediatrician and Nurse Consultant, plus on an ad hoc basis Clinical Nurse Specialists for specialities have attended too, Youth worker-invited but have multiple commitments and have found it difficult to attend, and work is ongoing to encourage regular attendance.

Social care has strong representation within the group, as it is attended by the service manager for transition and progression and the LD transition liaison nurse.

Led and Chaired by the Lead Nurse C&YP who ensures that all attendees are aware of the importance of the group. The chair also monitors attendance to ensure all agencies are represented.

The group also has a parent member and has carried out some consultations with young governors from Sheffield Children's Hospital. The Young people shared ideas about what they wanted to know during transition and what they wished to see improved. Individual care groups have developed specific Picker surveys with Young people. A programme has commenced in a number of specialities.

Work undertaken by the group includes the following;

- A document that contains the Sheffield Children's Hospital (SCH) and Sheffield Teaching Hospitals NHS Foundation Trust (STH) contacts for transition across all the clinical specialties. This is updated on a 6 monthly basis shared with the group and in STH is available on the intranet site for Children and Young People.
- Nursing Care Guidelines have been produced and are to be reviewed bi-annually (appendix 3). The guidelines detail the transition process for all specialties, assisting in ensuring

consistency for service users across services.

- A Transition Pathway; a generic pathway has been devised which is available on the intranet site for other specialties to use to develop their own pathways and is the basis for all transition planning across the specialties in health services, further ensuring consistency for service users. (appendix 4)
- A service wide share and spread Transition study day is planned for June 2011.
- Information; Development of a generic transition leaflet between Sheffield children's hospital and Sheffield teaching hospitals. A Sheffield Teaching Hospitals young person's web site and an information pathway for young people with learning disabilities. Coordination of Transition events at local special schools attended by health staff for parents staff and young people preparing for transition.

Aims and Objectives

The Task group aims to facilitate consistently high standard transition planning in children's and adult health care services across all specialties. The group aims to provide the tools with which to plan, the guidance with which to maintain a consistent approach for young people and information for all professionals and young people so as to alleviate anxiety and facilitate a smooth transition within health services. The task group will ensure robust links with local authority social care, in order to ensure early identification of need and facilitate effective planning by providing information to local authority professionals. The group has education of staff as one of its core aims and details meeting of young peoples needs as another.

The group aims to improve the pathways for all young people transferring to adult services across all specialties in the Trust, by ensuring:

- ❖ Development of appropriate pathways for young people to transfer to adult service
- ❖ Each clinical service across STH NHS FT will identify a lead person to support the transition of care of young people to adult hospital services.
- ❖ As young people are identified a full assessment will be undertaken by the Clinical Lead or Clinical Nurse Specialist in partnership with the adult hospital services clinical team. The formal assessment will be the first part of the joint transition plan to support the young person entering into adult hospital services.
- ❖ Personalised, assessment which will include the young person's domestic arrangements, their health needs, their social and educational needs with the provision of help and advice from an appropriate and informed professional or legal guardian/next of kin.
- ❖ STHFT will participate in and support a joint clinic for the purpose of transition of care which should be held on the appropriate hospital site. During the last year of transition the clinical appointment should be held in the adult Trust to ensure the young person has an awareness of the adult hospital service they have been referred to. As part of their appointment a transitional care plan will be completed and copies will be retained by the referring Trust, the receiving Trust, their GP and the young person.
- ❖ Support of a co-ordinated approach in the planning of care of the young person. Ensure professionals Provide appropriate written communication to support the young person.
- ❖ Each service will establish robust systems of checking and follow up arrangements in line with Trust guidance for young people that do not attend clinics

Approach

With an emphasis on consistency and, sharing of good practice, the group planned to improve transition pathways, for young people across all specialities. Planning is facilitated by the group and its chair and the group meets bi monthly in order that progress and next steps can be efficiently and equitably planned across services.

This is an ongoing project in order to develop and improve provision of support and information for children with learning disability and complex needs transferring to adult services. The groups have no set timeframe in which to deliver overall improvements, each element of development is assessed and

timescales agreed and applied at each stage of the improvement process.

Following the original audit, there is ongoing 6 monthly reporting back into the Trust Exec group which necessitates effective application of timeframes for individual elements of the groups work. Key to the success of this work is the strong leadership and executive level support offered from the groups chair and trusts exec group. A range of stakeholders are identified who attend the task group which includes colleagues from Health, Sheffield Children's Hospital, Social Care and members of LiNK. There are also identified leads in care groups who attend the Transitional Care Group Meeting. Finance is managed in house as part of developing the

transition pathway

The group facilitates transition planning processes for all young people transferring to adult hospitals. Managed by Phil Scott Lead Nurse CYP she Initially developed an information sharing document to identify the named professionals in the children's and adult hospital for all specialties, convened the group and began to put in place development plans to address identified needs as resulted from the audit.

Challenges

As with most initiatives of this nature, professionals recognised the difficulty in involving young people and their families in a meaningful way so decided to gather views from young people separately.

This was facilitated with one to one and small meetings with individual young people and parents, accessed via a number of routes, including, Clic sergeant (charity support service for children and families with cancer) and social care via a scheme that is exploring cancer survivorship. Further participation and consultation methods are being explored.

Successes

Meeting timescales in order to develop information has been a challenge and remains a key success of the task group. Feedback and input from the staff who are involved in the task group is the biggest contributor to its success. Clear lines of communication and strong leadership and strategic level support for the work has enthused staff and driven improvements in this area. Evidence from the initial audit galvanized support for the task groups' formation and specifics of the audit and continuous consultation with young people continues to ensure task group members prioritise the development work of the group.

The skills and enhanced knowledge of high quality transition care and planning, and the

ability to become involved with families requiring support during the transition process is of major benefit to the professionals and young people in Sheffield.

Feedback regarding the documents, information and new processes around transition for health services is obtained locally in care groups, the Matrons have been coordinating complex cases and have received positive feedback and evidence from the NCRI, Cancer Survivorship Project of experience of transition in Sept 2010 (not learning disability) also provides evidence that the transition process is improving.

Feedback will be obtained in detail during "picker surveys", in brief specialties have set up surveys, which ask 10 generic and 10 specific to specialty questions about the transition experience. The patient partnership department has been asked to deliver training to young volunteers who will visit out patient departments and ask/ assist young patients to complete the surveys on a hand held device. The data will then be analysed and used by the group to further develop action planning around specific and generic transition pathways. This area was identified as lacking in the initial audit and has been developed to gather feedback from young people's experiences. First round picker surveys are due to commence in GUM, rheumatology and metabolic bone clinics in May of this year. Plans to expand the surveys are still in development.

Conclusion

The group has already achieved improvements in up to date information and pathways for staff to access to support the process, in publishing online the guidance documents to support transition and nursing guidelines. Production of leaflets in some specialties and a web site for young people to access is already in development. The group has successfully improved staff knowledge and as events take place more staff will have the relevant skills and knowledge with which to appropriately facilitate the transition process. Better pathways for

transition care for Young People and their families, are being developed continuously and enthusiasm to improve outcomes for young people is tangible within the group's membership.

The Need to engage all levels of staff; i.e. allied health professionals, clinicians, and clinic staff to ensure appropriate appointments are booked for these patients, is well recognized and continues to be a focus of enabling better transition planning. There is an in house transition study day booked for 16 June 2011. Young People and their parents are invited to speak at this event to share their experiences within the organization. There is also access to Transition/ Communication skills e-learning package in house through the OLM E Learning System, which can be accessed by all staff.

Tips for setting up a Multi-agency Transition work group.

- Scoping exercise to identify relevant stakeholders from each specialty, include young people.
- Identify “champions” clinicians who are enthusiastic and can assist in driving the initiative.
- Solidify reporting structures and strategic level support. Audit of existing service may assist in highlighting this area as priority need.
- Set clear terms of reference for the group
- Develop an action plan, generic pathway , guidelines and policy
- Set up internet page with relevant literature so staff can learn independently
- Develop training tools and implement a programme of how to use them
- Gather feedback.

The following appendices can be viewed separately:

- 1. Caring for Children and Young People**

within Sheffield Teaching Hospitals Audit Tool (2007 version)

- 2. Transition task group terms of reference**
- 3. Guidelines for Transition of a young person into adult services**
- 4. Guidelines for Transition of a Young Person into Adult Hospital Services**
- 5. Example web page, Children and Young People website**
- 6. Sheffield NHS foundation trust Transition leaflet**

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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

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