Preparation for Adulthood - Scrutiny Board
Leeds Community Healthcare (LCH)
February 2016

The transition of young people into adulthood is a complicated journey for all, but often much more so for our young people with Special Educational Needs and Disability (SEND).

There are two key aspects to healthcare transition of young people from children to adult services:

1. The safe handover of healthcare provision for young people from one service to another, and ensuring that each young person knows where to go for ongoing care.
2. The role of health professionals in working with young people, their families and the rest of the team around them to prepare them to live life their way.

Both aspects have their challenges, with work ongoing across all services to continue to improve the experience of young people and their families at this critical time in life.

1. Safe handover of health care for young people with complex needs moving into adult services

Health care in Leeds is provided by three different agencies: Leeds Community Healthcare NHS Trust (LCH), Leeds Teaching Hospitals Trust (LTHT) and Leeds and York Partnership Foundation Trust (LYPFT). Each of these organisations is made up of a number of different services with different management structures and commissioning arrangements, criteria and functions. There are very few instances where a service provided for children has a directly equivalent service for adults. Specialist services for children are mostly designed around young people with disabilities that have been present at birth or soon after, whereas adult services are largely designed around people who acquire disabilities late in life. Therefore, there are some inherent challenges to the transition process that health service providers and partners need to keep working on to reduce the impact of these challenges on young people and their families. Current practice regarding transition of care provision is as follows:

Transition of medical and therapeutic care for young people with disabilities
The ***community paediatricians*** have developed a consistent city-wide approach to transition for young adults with neurodisability. There are annual clinics in each of the 3 wedges of the city and include (as appropriate to the needs of the young person):

- Community paediatrician (children's service, LCH)
- Consultant in paediatric neurodisability (children's service LTHT)
- Community Neurological Rehabilitation Team (CNR) (adult service in LCH)
- Learning Disability team (adult service in LYPFT)

This process is continuing to be refined with further clarification of pathways. It is planned that the broader multi-disciplinary team will be brought into this process now that the medical handover aspects are established.

The ***occupational therapy*** and ***physiotherapy*** teams transfer young people who are open on their caseloads to the relevant services, either the CNR team or the Learning Disabilities team. This is done through provision of written information detailing the current goals the service has been working on with the young person, and key information to inform future care. Transfer of care is done on a case by case basis, and where relevant, is done in conjunction with the social care transitions team.

The ***speech and language therapy*** team transfer young people to LYPFT learning disability service where appropriate. The communication aids service and stammering service see both adults and children, so young people stay in the same service.

The ***learning disabilities*** team based in the CAMHS service transfer young people to the adult learning disability service. They work alongside the social care transitions team as part of this process.

The adult ***Community Neurological Rehabilitation*** Team uses multidisciplinary goal based input towards increasing independence and managing the transition into college/ university/ work place. They work to episodes of care but are aware that young people often have changing needs over this period which require input over a longer period of time. They do not provide single discipline "maintenance" therapy. A recent qualitative research project carried out by a medical student in the service has identified a lack of services for sexual function for young people with neurodisability and this is an area of development for the service.

Transition of nursing care

The ***children's community nursing team*** consult with the adult District Nurses from 6 months before a young person is due to transfer to the adult team. They ensure the family are aware of the new team and that the new team know all the relevant information about a young person before the transfer happens. Young people with highly complex needs occasionally need to be handed back to the hospital for follow up care if the DN team do not have the relevant competencies to provide the support required, though this is very rare. The children's nursing team also work alongside the transitions worker if one is involved. The adult continence service is informed where appropriate.

Children's continuing care and short breaks team – young people receiving continuing care support usually transition to the adult continuing care team. This is done in consultation with the young person and family, and is planned in advance of the transfer of care. Start and end dates of care provision are negotiated with the new team and the family to ensure this process goes smoothly and safely.

Hannah House – The team work closely with the family and the transitions worker where one is involved. Some young people will move into social care provision when they move into adulthood, while others will continue to receive health support. The team provide support to the family throughout the process. Not all young people have a transitions worker, as not all have had social work support, which can make life more difficult for families. Families are encouraged to self-refer their young people to adult services social care on their 18th birthday so they can receive this support.

Transition of mental health care (please see separate document)

2. Health professionals supporting young people to live life their way.

All LCH children's services are involved in supporting the implementation of the SEND reforms in the Children and Families Act. All services contribute to the Education, Health and Care planning process around a young person when invited to do so. This is done through submission of information and/or attendance at planning meetings. Work is underway to improve these processes, particularly in relation to SILC EHC conversions, where there has been some initial difficulties ensuring that the right people are informed at the right time to ensure they are able to contribute appropriately.

Clinicians work alongside young people, families and colleagues in social care, education and the transitions team to contribute to the broader planning around preparation for adulthood. Health professionals provide advice, strategies and training to young people and their support teams to enable them to participate fully in their lives.

Health professionals are also involved in multi-agency processes that support planning for both individual young people as well as broader planning around strategic developments. Examples include:
- Physical Disability and Medical meeting
- the Multi-Agency Panel for decision making around EHC assessment
- Interagency Children's Equipment Working Group
- Children and Families Act Steering group
- Complex Needs Partnership Board

Areas for development

There is work underway on developing better processes and pathways within and between services to make the transition process smoother for young people and their families. The following areas are recognised as needing particular attention:

Coordination of care needs to be started early so that by the time the transition to adult services is occurring, this is a natural extension of an ongoing process. Trying to coordinate care at the end of a young person's journey through children's services is unlikely to be successful.

With this in mind, there is significant work going on across children's services to coordinate care around children across services and across agencies. The current focus of this work is transition into school, at the request of health commissioners. Significant work is going into building more cohesive care plans across professional groups based on the child and family priorities. The plan is to roll this out to all children and young people in these services over time. The next group for specific attention will be those in Year 9 and preparing for transition to adulthood.

Young person and family centred care is an area for further development within health. This is a change in ways of working for many health professionals. LCH is investing in staff training on child- and family-centred goal setting and health coaching to ensure professionals are confident in supporting young people to identify what they want and need from their health care so they can achieve their own goals. LCH is introducing outcome measurement focused on child and family goal-setting and their experience of care. The Integrated Children's Additional Needs Service is currently working with commissioners on implementing this change. Children's services also need to be more active in supporting young people to take control of their care at an earlier age, so they can be more confident in managing their health professionals when they move into adult care.

Clearer ***Pathways*** for key areas that matter to young people and their families would support smoother transitions by helping young people feel more in control and prepared for adulthood. A number of these have been identified as priorities for the year ahead, based on feedback from both families and services. Pathway work will involve agencies working together with young people and families to ensure these are designed to provide the support needed in a seamless and timely way, making best use of the resources available.

The priority pathways for the next year are:

- continence
- eating and drinking
- sleep
- behaviour
- family support
- postural care and pain minimisation
- sexual function (Adult service led)

Leeds Community Healthcare teams are committed to improving the outcomes and experience of our young people and families. We look forward to working with the council and our colleagues across all agencies to ensure young people with SEND move into adulthood with confidence that they will receive the support they need to live life their way.