Supplementary information for Scrutiny Board (Children's Services) on 25 February 2016

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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.

Transition between Child and Adolescent and Adult Mental Health Services in Leeds

1. Background

In Leeds, the Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) are provided by different organisations – Leeds Community Healthcare Trust (LCH) and Leeds and York Partnership NHS Foundation Trust (LYPFT) respectively. The mental health needs of children and those of adults can be seen as different and, to some extent, this reflects social and cultural expectations. However, this apparent difference is not something that immediately appears on their 18th birthday, and so transition between the two services needs to be sensitive both to each individual's needs and to the roles of the services available across the city for people with mental health problems.

In order to provide a universal standard for aiding the transition between CAMHS and AMHS, a protocol was developed between LCH and LYPFT. This has subsequently been modified following feedback from Young Minds and qualitative interviews undertaken by the Transition Team. The Transition Team consists of one Band 7 senior mental health practitioner and one band 6 mental health practitioner who are employed by LCH to support people in making a transition from CAMHS where ongoing mental health input is needed. The protocol is currently being revised, but the underlying principle is that different mental health providers should work collaboratively to make the transition for young people as smooth as possible and ensure that the young person's needs take precedence over the needs of the service providers.

2. Transition protocol between Child and Adolescent Mental Health Services and Adult Mental Health Services

The objectives of the protocol are as follows:

1. To promote a collaborative and flexible working practice between CAMHS and AMHS.
2. To clarify and define roles and responsibilities in the process.
3. To ensure that good practice is shared across the city to ensure a universal approach.

2.1 Age of Transition between Child and Adult Services

CAMHS provide services for young people until their 18th birthday. In order to allow sufficient time for planning and preparing the young person for the change, professionals involved in the young person's care are alerted when the service user reaches 17½ years. At this point there will be discussion between services as to the most appropriate approach. Because of the nature of child mental health problems and the variety of services available in the city to provide mental health care for adults, not all young people receiving care from CAMHS will be best suited to a direct transfer to adult mental health services within LYPFT. If the young person is thought to need input from adult mental health services, the transition worker will be involved and facilitate this transfer.

Where a young person approaching their 18th birthday is referred for initial assessment, there is direct discussion between the child and adolescent and adult services to agree which should take a lead. Often the transition workers will be directly involved in the process.

2.2 Process of transfer

Most young people seen by CAMHS will not need a direct transition into adult mental health services. There is flexibility within CAMHS to allow for specific pieces of work to continue beyond their 18th birthday, and group work can continue within CAMHS even when the rest of a

young person's care has been transferred. This flexibility acknowledges that therapeutic interventions do not necessarily have a specific age cut off, and also that young people's needs vary within a similar age group.

Young people are likely to need transfer to AMHS for the following reasons:

- Ongoing symptoms or effects of a severe and enduring mental illness
- Ongoing symptoms regarding risk or reduced social function linked to mental health problems
- Other mental health needs are likely to continue to need the input from specialist mental health services

It would not be expected that transfer of care would occur during an acute episode as this would not allow for the appropriate longer term planning that is necessary in achieving a successful transition.

Where a young person is thought to need input from AMHS the initial contact between CAMHS and AMHS will be a professionals meeting. This is specifically so that the young person is not involved in detailed discussion about specific service criteria and eligibility, and to promote a smoother transition to an appropriate service. It was reported by young people that being involved in early discussions when an adult service was not appropriate was often seen as a rejection. When an appropriate service is identified a joint review involving the CAMHS clinician/transition worker, adult mental health worker and the young person (with family where appropriate) will be arranged.

The professionals' meeting and this joint meeting are designed to ensure that serial assessments are not required. If a young person has been under the care of the CAMHS service there should be sufficient information to allow clinicians to determine the appropriate service for any ongoing mental health needs and also to develop an appropriate initial care plan. Following this meeting there would be a period of joint working to promote a smooth transition.

3. Specific Services

3.1 Young People with First Episode Psychosis

The Early Intervention for Psychosis Service within Leeds is delivered by Aspire (Community Links), who provide a service for people aged 14 years upwards. Therefore, young people with first episode of psychosis do not require a transition between services, but within Aspire there would be a transfer of care between psychiatrists. This would be managed by Aspire and the allocated worker.

3.2 Specialist Services

Because of the specific referral criteria, there are individual protocols in place for transitions for young people with Learning Disability, Eating Disorder, Gender Identity Disorder, Attention Deficit Hyperactivity Disorder, to the Personality Disorder Clinical Network, IAPT and the Women's Counselling and Therapy Service. The principles underlying these separate processes remain the same as those described above.

4. Monitoring Arrangements and Feedback

The protocol described above is developed and monitored through a quarterly meeting between AMHS and CAMHS. This is co-ordinated by the transition workers. Specific challenges are

brought to the forum so that there can be shared learning across the city, and when needed, improvements to the process made.

In addition, the transition workers are invited to the Leadership Forums for the three locality areas and the Crisis Assessment Service (CAS), on a quarterly basis to allow more direct contact with senior clinicians and again to identify any needs should they arise. The locality community teams also have an identified link worker for the transition workers to make contact with.

Most recent figures available reveal that between November 2013 and November 2014, 73 referrals were received by the transition workers and all were taken on for direct work. This is an increase from 52 referrals for the previous year. This increase has been supported by the addition of the Band 6 worker described above.

Annual feedback from clinicians, young people using the service and their families has been very positive. All clinicians were extremely satisfied with the service and only one young person made the transition to adult services feeling unprepared. In particular, young people appreciated not having to 're-live' their past through reassessment and being clearer about which service they would be involved with in the future.

5. Challenges for the Transition Service

Anecdotal evidence suggests that when the transition workers are not involved in a young person's move to adult services the experience is less satisfactory. It is not clear whether the Band 6 worker will provide sufficient extra capacity for the service to proactively identify young people aged 17½ years to ensure that future mental health needs are considered and met. In part, there needs to be a greater awareness and use of the transition team within the wider CAMHS.

There is a potential role for peer support to work with young people to aid transition into adult services or support young people leaving CAMHS to not require ongoing care within adult services.

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