# Audio file

[Transitions- what happens to health services on transition.mp4](https://lbwf-my.sharepoint.com/personal/adela_harewood_walthamforest_gov_uk/Documents/Transcribed%20Files/Transitions-%20what%20happens%20to%20health%20services%20on%20transition%20(1).mp4)

# Transcript

Hello, my name is Vicky Monk Meyer. I'm designated Clinical Officer from Waltham Forest and I'm going to talk to you about transitions and what happens to health services on transition to adulthood.

One of the things that families and young people ask most often about transition is what will health services look like in adulthood.

Part of these presentations is to tell you about what decisions you need to make and when, and who to ask about adult health services.

Many young people with complex health needs are seen by the consultant pediatricians at Wood Street. They may discuss with yourself and young people adult services from the age of 17 and a half. There'll be a review in the last year between 17 and 18 whether onward referrals will be discussed with you.

Adult services might include services for people with neurological conditions such as cerebral palsy or epilepsy. If your young person has autism for instance, and is no longer under the consultant, you may be referred back to your GP for monitoring.

There are some adult services that I'll talk about later, that they might be discussed with you.

If your young person is under CAMHS (child and adolescent mental health services), there will also be a final review and they will discuss with you whether they will be referrals on to adult mental health services. If your young person has a diagnosed mental health condition, or whether they would also refer you back to the GP.

[00:01:38] This slide is about who will make the referrals. If you're under a consultant paediatrician or if not, whether you're still seen by people like the school nurses or the therapies.

So for young people with complex health needs, attending a special school, the review will be held with the consultant, pediatrician and the referrals will be made by the pediatrician. For the young person who's on a specialist pathway but is not at a special school, you will have your final review and the referrals will still be made by the consultant pediatrician.

If your young person is receiving specialist services, but it's no longer seen by the pediatrician, so you might already have been referred back to your GP some time ago, then onward referrals to adult services if necessary, might be made by school, nursing or therapies.

And for young people under CAMHS, the last review will be made with the consultants who are looking after your care. That might be a psychiatrist, or it might be a psychologist, and onward referrals will be made to the GP.

The types of adult services your young person receives will be decided on their health needs, so the complexity of their health needs and also the level of learning disabilities.

The next slides [00:02:46] are about how those decisions are made.

Some adult services will ask if your child has a learning difficulty or a learning disability. It's important that you ask at annual reviews and opportunities with your consultant pediatrician as to whether they think your child has a learning difficulty or a learning disability.

Learning disabilities are described as difficulties with a young person having delayed language skills, difficulty making decisions for themselves, or difficulties in multiple areas of daily living, such as looking after themselves, study skills, self-care, etcetera.

For a person with a learning disability, they're not likely to be taking accredited exams, although some may take a small number. And they may be taking something like asdan, a young person with a learning disability might need considerable support to travel independently. That's not to say that they're not unable to do so, but they might need to learn a route and need support initially to practice that route and find it difficult if changes are made.

Usually a person with a learning disability is not able to read and understand a book or part of a newspaper, although they may well be able to read some or part of the information, they might not be able to read the whole amount and apply the information.

You may have had an assessment of your young person's IQ. In that case, you may be clearer as to whether the person has a difficulty or a learning disability just from an IQ score.

However, this isn't often something that's used in isolation, and services will often want to know about their general activities of daily living.

From the age of 16, young people should be making as many decisions as possible about their own preferences and about their future. Young people may be able to make decisions about certain things around their future, but perhaps not others, and you could might hear this called a decision around their mental capacity.

For instance, a person with a learning disability might be able to decide what they want to eat or drink, or what clothes are suitable for the weather that day, but not might not have the capacity to be able to decide where they want to live or who they want to live with.

These types of things may be considered in a best interest meeting if that is the case. So for instance, professionals may meet together with the young person and consider whether they have the capacity to make the decision about where they want to live and look at what's in their best interests and what information they require or support they require to make that decision.

If they're not able to make that decision even with high levels of facilitation, professionals may have to make that decision for them, and this is described as a decision made in their best interest. This happens very rarely and in adulthood, as many decisions as possible are made with the young person and all facilitated in order for the young person to make the decision.

It's quite difficult to understand if you're coming from a perspective as the parent and carer, because young people make make decisions that are not wise. For instance, they might choose to drink alcohol and you don't think they should, or they might choose not to take certain medications. All of those things need to be talked through with the professionals working with that young person. So you understand your own role and the professionals role and the child's role in the decisions they're trying to make.

There's a bit more about this on the links I've put on this slide.

Next, I'm going to talk to you about what happens to health services when a young person stays on in education. If the young person has therapy specified in their education, health and care plan and they are still in a special school, the therapies will be provided up until the age of 19 years.

If the young person has been attending school and move to a college place and they still have therapy specified in their education, health and care plan, the college may ask for funding in order to source this speech and language therapy. For instance, occupational therapy for that child.

Some of the therapy services, after 18 years, may go on to be provided by local teams such as the Adult Learning Disability team or by a local hospital. This is the case often for physiotherapy. If your child has physical needs and has equipment such as a specialist chair, that equipment will move with them to their new college. Because it's been assessed and prescribed for them specifically, it will stay with them until they leave education or until such time as they are assessed that they require a new one.

If you are staying and all in education, post 18, you may ask for a personal budget for your therapies. This is something that needs to be agreed with the local authority and health services in order for it to be provided, and is usually only agreed if the local services are unable to provide the therapy that’s outlined in your child's education, health and care plan.

[00:07:43] The next part of this presentation I'm going to talk about services for people in two different ways.

First, I'm going to talk about services for people with learning disabilities. You might remember we mentioned this earlier and then later I'm going to talk about services for people with learning difficulties.

The young people in Waltham Forest, who have a learning disability, they're highly likely to be referred to the Community learning disability team. This is a service of a mixed team of speech and language therapists, occupational therapists, physiotherapists, psychologists and psychiatrists who all work together to meet people's needs, who've got a learning disability.

The team will accept the referral and do an assessment, and one of the first things they will try and decide is whether the person is eligible for services, so it's very important if you can to provide any information around the disability that your young person might have. You can read a bit more about them on that link.

The team work together to decide whose best place to meet the young person's needs, so it might be that an occupational therapy is leading your child's care, or it might be a psychiatrist. I'm also going to talk about meeting your child's physical needs in adulthood.

Young people with highly complex health needs, such as falling cerebral palsy or autism with learning disabilities, may be eligible for continuing health care funding in adulthood. This is funding that comes directly from health in order to provide services which might not ordinarily be available.

If this is the case, then your social worker or your school nurse will do a decision support tool, which is a checklist that looks to see if a full assessment should be carried out to see if someone is eligible for continuing healthcare.

It's important that you try and keep reports available so that you can provide this to whoever is trying to do the decision support tool to support that process.

You may you could find out a little bit more about this by looking at the Beacon website or by calling the number. If a young person is eligible for continuing healthcare funding in adulthood, it might be provided in terms of services, or it might be provided in terms of a personal budget, which you can then use to find a PA or someone who can support you and your young person to go about their daily lives.

If your young person continues to have physical needs in adulthood, they may be referred on to other community services. For instance, if a young person has skin problems such as risk of pressure sores, they may be referred to district nursing services by their school nurse. If they continue to use continent products for their personal care, school nurse may also refer on to the continent services in adulthood. Your physiotherapist or your GP may refer your young person onto orthotics or Podiatry if they continue to need these services, you might have to monitor your child's orthotics or the young person’s your orthotics to see if they're wearing out because often need services work on a self-referral basis and you'll be expected to be able to contact them to say that the review is required.

(00:10:58) The following information is around mental health services in adulthood and is most likely to be applicable to those people who have a learning difficulty rather than a learning disability.

If you're a young person, is still under CAMHS at the time of 18, a decision will be made with the consultant seeing them and yourself and the young person as to whether they need referring on to adult mental health services.

Adult mental health services thresholds is around people who have a diagnosed mental health need. You can read a bit more about this on the NEFLT websites for these links I've added them onto this slide.

If they do not have a diagnosed mental health difficulty, they may be referred back to their GP. However, you could still access talking therapies and there's also a 24-hour advice line if you're at all unsure or you're feel that your mental health needs are changing.

I've also added some information here about the autism services in adulthood for those who don't have a disability. You can still go on to have an autism diagnosis and adulthood. You can be referred by your GP if this is an area that's not been assessed for under 18. The service does diagnosis pre and post diagnostic support. If you have an existing diagnosis of autism, the service also may provide some advice for any health professionals working with you and also for yourself if you need some further help on how to access services.

If your young person has a diagnosis of ADHD pre 18 and are taking medication, CAMHS will refer you on to adult ADHD services. Adult ADHD services may review you if you haven't had a medical review for a while and make sure that the medications that you're receiving are meeting your needs, they may discuss with you any other services you may require. For instance, if they are also starting to experience anxiety, they may refer on to other mental health services in adulthood.

Once you're settled in your medication and a review is being carried out, you may be referred back to your GP in order for them to be able to continue your care.

Next, I'm going to talk to you a bit about the dynamic support register. The Dynamic Support Register is a list of young people held by the ICB, which is the commissioning team who have autism and or learning disabilities.

These people may be at risk of hospital admission or placement of their home breaking down due to reasons of their mental health. The ICB holds the list and meet with local providers to see if there's anything they can do to make sure that young people don't end up in hospital unnecessarily or have breakdown in their family or home life.

The list, held in children's goes up to 18 and in the adults it's from 18 onwards. In adults, the list is held by the adult Community learning disabilities team, and it's often those who have a learning disability plus autism, who are considered on this adult register.

If your child is on the child's dynamic support register, it's highly likely that they would transition to the adults dynamic support register and you'll be told a little bit about this at 17 and a half and usually be you told by a social worker or a school nurse.

You can read more about the Dynamic Support register on the local offer under this link [transforming care people with learning disabilities and autism](https://www.walthamforest.gov.uk/schools-education-and-learning/local-offer-special-educational-needs-and-disability-send/social-emotional-and-mental-wellbeing/transforming-care-people-learning-disabilities-and-autism). You can refer yourself onto the dynamics support register or be referred at anytime by parents or a caregiver.

These last few slides are about taking care of your health in adulthood and also how you can make sure that people you're coming across in day-to-day life know about your health needs. I talked earlier about understanding whether your young person has a learning difficulty or a learning disability.

If you're a young person, has got a learning disability, it's important that their GP is aware, the consultant, pediatricians or yourself, or any therapies, can write to the GP and ask for your young person's name to be added to the learning disability register.

This means that they would have a yearly health check that goes through general health needs that may be more commonly overlooked, and people with learning disabilities, partly because they find it very difficult to express changing physical needs or if they feel unwell it might be unclear as to what their particular symptoms are.

The more their GP knows about the young person, the better, and if any changes are then become apparent, their health needs can be picked up more quickly.

Young people with a disability can have a check with their GP from age 14 onwards. The doctors will invite you to the check. There's a little bit more about what to expect from these types of checks on those links at the bottom of the slide, but essentially it will be basic health such as heights and weights. Listening to your heart talking about things like sexual health. Also remember to talk about digestion such as Constipation or any diarrhea and also things like menstruation. These are types of things that can be difficult to talk about with people in your life. But it's important that your GP knows that there's any changes to these types of things in your health. If you or the young person you care for needs to go to hospital, it's really good to have a hospital passport which will help make that trip into hospital easier.

The hospital passports can be written by yourselves as a parent or carer or by the young person themselves if they're able, and they summarize current health needs in order to make it easier in a stressful and difficult situation to explain what the needs might be when you go to hospital. There's links on this website to how to write a hospital passport and what to include.

If you need help with writing the hospital passport, please do ask those who know your child or yourselves, so it could be a school nurse. It might be a therapist who can help you write the passport.

And don't forget to tell people if you're worried about going to hospital or going into to your GP so we can help with any accessibility needs.

This last slide contains some links to organisations locally that may be able to provide you advice and support about health services in adulthood.

I hope you found this interesting and please do [e-mail me](mailto:vikki.monk-meyer@nelft.nhs.uk) if you have any questions you'd like to ask me about transition into adulthood.

Take care and thank you very. Much for listening.

Thank you very much for listening for everybody and have a good day.