

Islington Care Pathway for Children and Young People with Down's Syndrome



Islington Parents Forum

Whittington Health NHS Trust, Islington NHS Clinical Commissioning Group and The London Borough of Islington working together to improve services for children and young people with Downs Syndrome

“Welcome to Holland”

By Emily Perl Kingsley, 1987. All rights reserved.

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very very significant loss. But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Parents' words

As parents of children with Down's syndrome, we know that the moment of diagnosis – and all that comes after – can feel quite disorienting.

This pathway is designed to help you identify the services available at each stage of your child's life.

You might not require all of them, or may need some more than others. You will find yourself mixing-and-matching specialist provision with the general activities available to all children, and you will notice that your child's needs change over time.

Aside from services provided by local education and health authorities, we have an excellent Down's syndrome support group locally (Downright Excellent) offering highly specialised therapies for our children from birth to their teens; over time, it has proven to be the best source of ideas about what we can do to support our children. We hope that you find the information contained within it useful and that you are able to access the support that you need.

Hopefully, we will meet you and your children in future. Until then, we wish you lots of joy raising them.

Laura and Jenny.

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1. Introduction

Context

Families accessing Whittington Health services in Islington have reported that there is little information regarding the offer for children and young people with Down's syndrome, and that there are no published guidelines on what support is available and when.

This document has been developed in partnership with parents and across agencies to provide a care pathway from identification to transition to adulthood for children and young people with Down's syndrome.

The pathway aims to achieve the following:

- Respond to the individual needs of the child.
- Provide equity of services.
- Promote understanding of services and referral pathways.
- Promote joined up working and working in partnership with families.
- Transparency.

The pathway does not replace those services that occur for all children such as primary care services, community health visiting or midwifery, but seeks to clarify additional services.

We propose that it be a dynamic document that is regularly challenged through audit, feedback and annual review.

What is a care pathway?

A care pathway is a systematic approach to describing and delivering the services and interventions that should shape care and treatment for a particular condition. A care pathway can be utilised in the translation of national guidelines into local protocols and clinical practice (Campbell et al 1998).

A care pathway aims to have:

- The right people
- In the right order
- In the right place
- Doing the right thing
- At the right time
- With the right outcomes
- All with attention to the patient experience

2. What is Down's syndrome?

Each human cell is made up of 46 chromosomes in 23 pairs. In the most common type of Down's syndrome, there is an extra chromosome on number 21, making 47 in total, hence the medical terminology **Trisomy 21 or T21**. Trisomy 21 is caused by an error in cell division called non-disjunction. This leaves a sperm or egg cell with an extra copy of chromosome 21 before or at conception. It is the most common autosomal anomaly, present in 1 in 600-700 live births.

There are two other less common types of Down's syndrome: **translocation** – where the extra chromosome 21 attaches to another chromosome, and **mosaicism** – where only some and not all cells have Trisomy 21.

Babies with Down's syndrome are born to mothers of all ages but the chance of having a baby with Down's syndrome increases as the age of the mother increases.

People with Down's syndrome have learning difficulties. This means they will find it harder than most people to understand and to learn new things. They may have communication problems and difficulty managing some everyday tasks. However, there is a wide spectrum of abilities, just like there is a wide spectrum in the general population.

Most children with Down's syndrome attend mainstream primary school. Much is now known about how to develop the potential of children with Down's syndrome. People with Down's syndrome can have a good quality of life with support from their family and others.

Some health problems are more common in people with Down's syndrome; for example, congenital heart defects, hearing and vision impairment, Alzheimer's disease, leukaemia, epilepsy, hypothyroidism, coeliac disease and obesity.

People with Down's syndrome have almond shape eyes and distinctive facial features but they do not all look the same. Like all children, they also inherit features from their parents.

3. Antenatal Care

Screening offered includes the Combined Test at 11 weeks.

In line with the UK National Screening Committee (UKNCS) standards all women who book in pregnancy prior to 20 weeks gestation should be offered screening for Down's syndrome (T21), Edwards Syndrome (T18) and Patau's syndrome (T13). The primary aim of screening is to enable women to make informed choices concerning their pregnancy outcomes.

First trimester combined screening for Downs, Edwards and Patau's syndromes is the preferred method of screening, as recommended by Public Health England and National Institute for Clinical Excellence (NICE). This screening test is undertaken between 11 weeks plus 2 days and 14 weeks plus 1 day of pregnancy. It uses a measurement at the back of baby's neck during your scan (the nuchal translucency, or NT) plus a blood test on the same day to measure free beta human chorionic gonadotrophin (β HCG) and pregnancy-associated plasma protein-A (PAPPA).

If it is not possible to obtain a NT measurement on the day of the scan, a test called 'quadruple screening' is offered instead. This is offered after 14 weeks and 2 days pregnancy and involves a blood test to measure alpha feta protein (AFP), inhibin A, unconjugated oestriol (UE3) and total human chorionic gonadotrophin (HCH). This test is also offered to women who book on or after 14+2 weeks, but before 20 weeks of pregnancy.

Results for both of these tests are expressed in terms of chances.

If the screening test shows that the chance of the baby having Down's syndrome is lower than 1 in 150 (for example, 1 in 200, or 1 in 2000) this is called a lower chance result. With a lower chance result the woman is not offered further tests.

If the screening test shows that the chance of the baby having Down's syndrome is higher than 1 in 150 – that is from 1 in 2 to 1 in 150 this is called a higher chance result. This does not mean that the baby definitely has Down's syndrome.

Women with higher-chance results are contacted by the screening team for counselling. The following options will be discussed with the woman: to have no further testing, to have a blood test called non-invasive prenatal testing (NIPT), or to have a diagnostic test such as amniocentesis or chorionic villus sampling (this should be available within three working days of the woman receiving the screening test result). The discussion includes: information to ensure that the woman is aware of the purpose, benefits, limitations and implications of NIPT and diagnostic tests, time of getting results, and possible results. Leaflets are given to support discussion. The woman is also given the contacts for relevant support organisations.

Antenatal diagnosis of Down's syndrome made – if a test shows a result that is positive for Down's syndrome, women are offered counselling and support regarding the decision whether or not to continue the pregnancy. Women who choose to

continue the pregnancy are then offered further care with the Fetal Medicine Unit including regular antenatal ultrasound scans and an antenatal echocardiogram (heart scan) at Great Ormond Street Hospital.

If the woman wishes to have CVS or amniocentesis, she will be given verbal and written information to enable them to decide whether to have the procedure. A small number of women who have the diagnostic test will find out that their baby has Down's syndrome. They have two options: some women decide to continue the pregnancy and prepare for their child with the condition; others will decide they do not wish to continue with the pregnancy and have a termination. All women faced with this choice will get support to help them to make a decision.

The **midwifery team** informs the neonatal team, health visiting team, GP and infant feeding coordinator when a woman is expecting a baby with Down's syndrome.

The **health visitor** will carry out an antenatal visit to mothers who decide to continue with the pregnancy. They will provide information about Down's syndrome including printed leaflets such as, 'Looking forward to your baby' published by The Down's Syndrome Association and available online at:

<https://www.downs-syndrome.org.uk/about/campaigns/tell-it-right-start-it-right/tell-it-right-information-pack/>

<https://www.downs-syndrome.org.uk/for-new-parents/being-pregnant/>

The health visitor may also start discussion about feeding your baby and can involve the Infant Feeding Coordinator to provide advice.

All babies with Down's syndrome identified antenatally are discussed before the expected due date at the joint Neonatal/ Midwifery meeting. A neonatal doctor is usually present at the delivery.

4. Postnatal Care – once your baby is born

When the diagnosis of Down's syndrome is made after birth

- When a diagnosis of Down's syndrome is not made antenatally but is suspected soon after birth, the midwife on the post-natal ward will ask the paediatric team to review the baby to confirm the diagnosis clinically.
- The diagnosis is then confirmed by a blood test known as a rapid genetic test. The result of this test is usually available after 2-3 days.

Postnatal care

- You and your baby will be transferred to the postnatal ward unless your baby requires admission to the Neonatal Unit (NNU) for medical reasons (see below). If on the post-natal ward, you and your baby may be offered a side room if one is available and, also depending on the clinical condition of you and your baby.
- Your baby may need to be admitted to the NNU if they are unwell. For example, if they require treatment or monitoring for heart problems, feeding difficulty or any other symptoms and signs that would necessitate admission in other babies.
- If your baby is admitted to the neonatal unit, you may receive some advice about positioning your baby, especially when feeding, from the paediatric speech and language therapist.
- The midwife will ensure that your baby can have as much skin to skin care as possible, even if the baby is admitted to NNU.
- If you are in hospital between 10-14 days the Health Visitor will still make contact with you and arrange to meet you either at home or at the hospital

Feeding

- Your baby will be referred by the midwife to the hospital Infant Feeding Coordinator (IFC) for an assessment of their feeding.
- If there are further concerns about swallowing or sucking, a referral to the hospital Paediatric Speech and Language Therapist (SLT) can be made by midwife or Hospital IFC.
- Similarly, if there are concerns about feeding with poor weight gain, a referral to the hospital paediatric dietitian may also be made.
- The midwife will be able to discuss breastfeeding with you. She will involve breastfeeding peer support where available. A useful guide to breastfeeding babies with Down's syndrome can be found here:
<http://www.lli.org/faq/down.html>
- If your baby has been admitted to the NNU they will be referred to the paediatric SLT.
- Breastfeeding support is provided by the Islington breastfeeding support and infant feeding specialist services. For full details see
<https://gps.northcentrallondonccg.nhs.uk/service/infant-feeding-specialist-service-islington>. Parents or professionals can contact 020 3316 8439

(breastfeeding helpline) or email

whh-tr.IslingtonBreastfeedingPeerSupport@nhs.net

Examination and investigations

- Your baby will be seen by the paediatrician who will carry out the new-born examination that all babies have within the first 24 hours.
- In addition to the examination there are a number of specific investigations. These include blood tests to check for possible blood abnormalities, thyroid and kidney problems, (see Appendix 1 for full details).
- Your baby will also have the routine screening tests that are universally offered to all babies. These include the new-born hearing screening and the “5 day Blood spot” test.
- Your baby may need the RSV vaccine (Palivizumab) for the winter if they have a specific cardiac or respiratory problem (such as a heart lesion with a left to right cardiac shunt or if they are oxygen dependant).

Information about Down’s syndrome

- You can speak with the midwife or the doctor to find out more about having a baby with Down’s syndrome. You can decide how much or how little information you would like.
- See resources from the Down’s syndrome Association such as 'A new parent's guide' <https://www.downs-syndrome.org.uk/for-new-parents/new-parent-pack/>
- Many families are interested in information about the following things:
 - Explanation of Down’s syndrome
 - Genetics of Down’s syndrome
 - Local resources for families with babies with Down’s syndrome
 - Down’s syndrome Association contact details
 - Information and advice about medical conditions associated with Down’s syndrome

Sources of information and support for families:

- **Down’s syndrome association:** www.downs-syndrome.org.uk Helpline: 0333 1212300 (10am-4pm) or Email: info@downs-syndrome.org.uk
- **Down’s syndrome Medical Interest Group:** www.dsmig.org.uk supports health care professionals working with children with Down’s syndrome.
- **Down’s syndrome education international:** www.downsed.org supports families, health care professionals, researchers and teachers
- **Down heart group:** www.dhq.org.uk a charity offering support and information relating to heart conditions associated with Down’s syndrome
- **Downright Excellent:** www.downrightexcellent.org provides highly specialist and syndrome specific therapies and quality play experiences for children with Down’s syndrome aged 0-16 and their siblings, plus education and support for parents/ carers & associated professionals e.g. nursery & school staff.
- **Islington SENDIAS (Family Action):** impartial support, advice and information on Special Educational Needs and Disability: <https://www.family-action.org.uk/what-we-do/children-families/.../islingtonsend/>

- **Positive about Down Syndrome** – a parent support group by parents for parents and parents-to-be: <https://positiveaboutdownsyndrome.co.uk/>
- **Afasic**: support service for people who have problems talking or understanding language and their families. Ring the Afasic Parents' Helpline on 0300 666 9410 during opening hours – Monday & Wednesday: 10.30am to 4.00pm. Web link: <https://www.afasic.org.uk/help-for-your-child/not-talking/afasic-helpline/>

Referral to community services

- Your baby will be referred to community services. This means referring your baby to Community Paediatrics and, where required, to Community Paediatric Speech and Language Therapy (SLT) and a Community Paediatric Dietitian. All babies that are fed by nasogastric tube (NGT) must be referred to the Community Paediatric SLT, Dietitian and Children's Community Nurses. (See Appendix 2 for community services referral form).
- The midwife will also refer your baby to the community midwife, health visitor, community IFC and breastfeeding peer support.
- In Islington we have a family therapist who is available to give support to parents who have had a baby with Down's syndrome. If you would like to receive counselling, please let your midwife or paediatrician know so that they can make a referral.

Discharge from hospital

Before you and your baby are discharged from the hospital, the midwife and doctor will make sure that the following have happened:

- Your baby is feeding satisfactorily.
- Your baby's weight is checked before discharge and plotted in your 'red book'.
- The Down's syndrome inserts for the 'red book' (the personal child health record book) will be given to you.
- A discharge letter is sent to your GP and Health visitor to inform them that your baby has a diagnosis of Down's syndrome.
- An echocardiogram has been done or arranged.
- You will have been advised about possible symptoms of undiagnosed cardiac abnormality.
- A plan has been made with you for how you would like the results of genetic test shared with you if this result is not available before discharge.
- Make sure all necessary referrals have been made.

Follow up by a Paediatrician

Your baby will be seen in the neonatal follow-up clinic at 4 to 6 weeks of age.



5. Community Care – the first six months

Bright Start Islington is our name for Islington’s services for under-fives and their families.

As well as childcare and early education, Bright Start Islington offers lots of activities and services for under fives and their families, including health visiting, stay and plays, and help to find work. Most are free, or low cost. You can also meet other local parents and parents-to-be in friendly, safe and welcoming venues across the borough.

Specific services for children with additional needs such as those with Downs Syndrome are also accessible:

- SEND stay & play sessions – accessible to all children with additional and special needs – parents enjoy time with their children in an inclusive environment with access to support and signposting by practitioners
- Universal Stay & Play sessions – all sessions are inclusive practitioners offer onsite support and signposting for families that have children with SEND
- Family Engagement Workers can meet parents of children with SEND at Family Support Surgeries for information, advice and guidance on specific matters
- SEND Priority Early Learning Panel (for children with complex needs) – specific funded nursery places according to children’s needs
- Free Entitlement for 2 year olds (Children with SEND claiming DLA) – 15 hours per week free nursery places
- Priority Early Learning Panel – priority nursery places with children who might have additional needs

- Family Support Practitioners support families with SEND children on a one – to-one basis in their homes (need referral or parents can self-refer directly)
- Visit www.islington.gov.uk/brightstart for more information about our services, venues and to find timetables. You can also contact the Family Information Service on fis@islington.gov.uk or 020 7527 5959
- Speak to your Health Visitor – call 020 3316 8008

Home visit

The community midwife will visit you and your baby in your home within the first 10 days. The 'new birth' home visit will be carried out jointly with your health visitor. The community midwife or health visitor will contact the community paediatrician- as soon as a date for the new birth home visit is confirmed- so that, where possible, the community paediatrician can also join you

Health visiting

Your health visitor will work with you and your family to provide an agreed enhanced programme of care and support including routine health reviews offered to all children. Please check out the website for more information:

<https://www.whittington.nhs.uk/default.asp?c=40906>

Community nursing team

For babies that are fed by nasogastric tube or dependent on oxygen, a referral to the community nursing team should be made. For Islington babies this will mean a referral to the Hospital at Home team.

Early Support Coordinator

You may receive some support from the early support team. The Early Support Coordinator will be able to help you support your child and plan their needs. Your health visitor or paediatrician can make a referral to the team.

The 6-week medical review

Your GP will carry out the '6-week check' (a universal screening examination which is offered to all babies). This is complemented by the health visitor 6-8 week health review which has a family focus which includes your own physical and emotional well being as well as that of your child.

Routine immunisations

Your baby will be offered all routine immunisations. There are no specific reasons why your baby may not be able to have these immunisations; in fact, as babies with Down's syndrome may have altered immunity and are at greater risk of infection, it is particularly important that they don't miss out on their immunisations.

3 month paediatric review

Your baby will be invited to an appointment with the community paediatrician when they are around three months of age. This appointment (in common with all subsequent paediatric appointments) is a chance for you to discuss any health concerns you may have about your baby and for the paediatrician to check your baby's growth and to ensure that your baby's hearing, vision and other screening

tests are carried out regularly. For more details of the paediatric appointments, please see Appendix 1.

Starting solids

Your health visitor will meet with you when your baby is around four months of age to discuss introducing solids at around six months as this can be more challenging in babies with Down's syndrome. There should be a low threshold for referral to community paediatric dietitian for further advice.

Increased risk of aspiration

Babies with Down's syndrome are at a greater risk of swallowing problems and food/drink 'going down the wrong way', i.e. food/drink entering below the level of the vocal folds into the trachea (airway). The health visitor or paediatrician should have a low threshold for referral to the community paediatric SLT if there are concerns about possible signs of aspiration which include coughing, choking, chest infections, breathing difficulties and wet voice quality. It is important to be aware that aspiration may be 'silent' which means that the signs are not obvious (e.g. no cough response when the food/drink/saliva enters below the vocal folds into the trachea [airway]).



6. Early Years – the first five years

The first year

Unless clinically indicated otherwise, paediatric reviews should be arranged at:

- 4-6 weeks
- 3 months
- 6 months

The paediatrician can refer to appropriate therapy services at any stage if required, i.e. if your child has a significant delay or difficulty over and above that which would be expected for a child with Down's syndrome.

Services may include:

- Physiotherapy;
- Dietitian and/or Speech & Language Therapy for eating, drinking and swallowing difficulties or behavioural feeding support;
- Occupational Therapy

The paediatrician will arrange to see your child again when they are 1 year old and after that appointments will be at least yearly or more often if needed.

At 1 year

The paediatrician will make a referral to early years Speech and Language Therapy for communication support.

The paediatrician can make a referral to other appropriate therapies if required, i.e. if your child has a significant delay or difficulty over and above that which would be expected for a child with Down's syndrome. Services may include:

- Physiotherapy;
- Dietitian and/or Speech & Language Therapy for eating, drinking and swallowing difficulties or behavioural feeding support;
- Occupational Therapy
- Health visitor one year health review - details of the review can be found in the 'red book' and on the Bright Start website

At 2 years

The paediatrician, health visitor or family support worker will discuss applying for a free early learning or childcare with you. This is free early education for 2 year olds. You can find out more by visiting [Free early learning for 2 year olds | Islington Council](#)

Your health visitor and key staff in your child's early years setting (if they attend one) will work together to carry out an integrated review of your child's strengths and needs. Referrals to other services can be made if needed.

At 3 years

All children are entitled to 15 hours education. Some families may be entitled to 30 hours if certain criteria are met. Find out more about free early education for 3 and 4 year olds by visiting: [Free early learning for 3 and 4 year olds | Islington Council](#)

Any professional working with your child can refer to the Educational Psychology Service if appropriate.

Professionals working with you and your child may discuss a Priority Early Learning SEND (PEL SEND) nursery placement with you. These placements come with additional funding so that extra support can be put in place. Children on a PEL SEND placement will have Educational Psychologist involvement whilst in nursery and to support transition to Reception

Between 3-4 years

Your child will have a Special Education Needs (SEN) support plan which outlines your child's strengths and needs, the goals they are working towards and how these goals will be achieved

Some children with additional needs will benefit from having an Education Health & Care Plan (EHCP). An EHCP is a legal document describing a child's needs, what should happen to meet those needs and the suitable educational placement. Planning for an EHCP should begin in the autumn term before a child starts Reception class the following September.

You can find out more about EHCPs by visiting:
[Education, Health and Care Plans | Islington Directory](#)

Children typically start Reception in the September before their fifth birthday. If your child was born between 1st April and 31st August, and you don't feel they will be ready to start Reception, you can ask to delay their start until the following year by contacting school admissions. You can apply for up to 6 schools – applications need to be made by the January and you will be informed of the outcome in the April.

For more information visit: [Apply for a primary school place | Islington Council](#)

7. Children's Therapies and Early Education

A wide range of services are available, if required. There are referral criteria which must be met for a child to be seen by each of these services.

It is not always necessary for a child to be seen by all or any of these different therapies. Following referral and assessment, appropriate therapy will be offered to meet the child's individual needs. The approach to a child's therapy will change over time to reflect their changing needs.

A successful outcome would be that children and families are able to continue without our input. If the child's needs change in the future we are happy for them to be re-referred.

Physiotherapy

Physiotherapists are responsible for assessing a child's whole body and physical (gross motor) development. They support with your child developing head control, learning to roll, sit up and move. They may provide advice and support until your child is walking. They often link with Occupational Therapy around motor development is supported through play-based activities.

Physiotherapists also may provide advice around keeping your child's chest clear (Chest Physiotherapy) linking with the Paediatric Speech and Language Therapist around feeding.

It is quite normal for children with Down's syndrome to have a delay in their gross motor development compared to typically developing children but they do make steady progress and learn to walk.

Referral

We accept referrals from healthcare professionals or from staff in education. The referral is then triaged and allocated to the relevant team if the referral criteria are met.

Assessment

Your child will be assessed in clinic possibly jointly with other health professionals depending upon their needs. We will use standardised developmental assessments and set functional physical goals that you would like your child to achieve. We will plan the treatment so the developmental physical goals can be met.

Treatment

Treatment is designed to meet the individual needs of your child and to ensure that the mobility and functional goals are met and their respiratory health is monitored if required. We work closely with parents, carers, nursery staff (if your child attends nursery) and other professionals involved in your child's care.

Therapy programmes may involve advice, individual sessions, group sessions. It may be delivered in a range of settings, such as clinic, nurseries and children's centres, the child's home or educational setting such as school.

Discharge

Your child will be discharged from the service when their functional gross motor goals have been achieved and their active mobility is stable. A maintenance advice programme is provided and can often be incorporated into routine activities. If your child's needs do change in the future we will be happy to see them with another referral from your GP or other Health Professional.

Occupational Therapy

Typically, children with Down's syndrome will have some delay in their development compared to typically developing children. Children learn and develop through play and sensory exploration and movement. Occupational therapists support you to help your child develop independence in play and activities of daily living such as feeding themselves, getting dressed, using the toilet, and developing their fine motor skills for educational activities, like learning to use a pencil or scissors. In some circumstances they may provide equipment or assess and advise around safety in the home environment.

Referral

We accept referrals from other healthcare professionals or education staff. The referral is triaged and will be accepted and allocated to the relevant team if the referral criteria are met.

Assessment

Your child will typically be assessed in clinic by the occupational therapist, though it may be possible to offer video assessment or home visit depending on circumstances. Occupational therapists work as part of the wider multi-disciplinary team. Sometimes assessment may be offered jointly with another healthcare professional depending upon your child's needs.

Initial assessment is likely to be play-based and will include discussion with parents/carer about how your child is managing with play, movement, and self care skills, like feeding or potty training, depending on their stage of development. We will also consider if your child has any sensory needs that are impacting on their development. We will agree functional goals that you would like your child to achieve.

Treatment

Treatment is designed to meet the individual needs of your child and to ensure that the functional goals met. We work closely with parents, carers, nursery staff (if your child attends nursery) and other professionals involved in your child's care.

Therapy programmes may involve giving advice, individual sessions or group sessions. It may be delivered in a range of settings, such as clinic, nurseries and children's centres, the child's home or school. We may sometimes recommend specific equipment to help your child in their daily activities at home or at school. We will share therapy programs and advice with nursery staff who are supporting your child. Depending on your child's treatment goals, we may sometimes work jointly

with the speech and language therapist or the physiotherapist, if this is the most effective way to meet your child's goals.

Discharge

Your child will be discharged from occupational therapy when have achieved the goals set with the family/carers and are managing their daily routines at home and nursery. If they require ongoing support once they are in school, we may recommend onwards referral to the school based occupational therapy.

If your child's needs change in the future, we will be happy to see them with another referral from your GP.

Speech and Language Therapy: Communication Support

Referral

Children learn and develop their communication skills through play and interaction with others. Speech and Language Therapists help parents and nursery staff become confident in using a range of strategies and activities to support the child's attention/listening, play, interaction, understanding and expressive language – both non-verbal (eg gesture, Makaton signing) and using spoken words. The majority of children with Down's syndrome will benefit from some additional help as they learn to communicate and to maximise their communication to their highest potential across their home, educational and social environments.

In Islington, there are lots of groups and activities offered as part of Bright Start (Islington children's services). There are 3 Bright Start areas: north, central and south. Some sessions are open to all children, for example 'Stay and Plays' and story and rhyme sessions. For some sessions, you will need to call beforehand and book a place; for others you can simply turn up on the day. Other groups are designed specifically for children with additional needs, for instance Chatterpillars and Extra Boost sessions – your child would need to be referred for these groups and your Speech and Language Therapist can do this.

You can find out more about the activities and groups in each Bright Start area and which age group each activity is appropriate for, by visiting the website: [Find Children's Centres and Bright Start Services | Islington Directory](#)

Your child can be referred to the Early Years Speech and Language Therapy service from the age of 1. Referrals are made by the community paediatrician or another therapist already working with your child.

Assessment

Following referral, the named Speech and Language Therapist for pre-school children with Down's syndrome will contact you to find out more about your child's speech, language and communication and to arrange an assessment of your child's strengths and needs. The assessment will be informal and play-based and will make good use of the information we get from you and, if your child is attending a nursery, from your child's keyworker.

Therapy

The support offered will be tailored to the needs of your child. Some of the ways the Speech and Language Therapist might support your child are:

- Ongoing assessment of your child's communication skills;
- Working closely with you and key staff at your child's nursery to set communication targets and share helpful strategies and activity ideas;
- Offering training to nursery staff, as appropriate;
- Offering evidence-based individual, paired or small group therapy to achieve specific speech, language and communication goals (these sessions may take place at your child's nursery or in clinic); and
- Offering workshops and training for parents and carers, e.g. Makaton Signing.

With your permission we will liaise with any other Speech and Language Therapists working with your child, e.g. if your child is working with an independent therapist or attending Downright Excellent.

Discharge or transfer

There may be times when your child's speech, language and communication needs are being met, by you as their parent and/or by their nursery, and so your child may be able to take a break from Speech and Language Therapy or require less frequent sessions depending on their needs.

The Early Years Speech and Language Therapy service sees children up until the end of Nursery year. Once children start in Reception class, if they require ongoing direct support from a Speech and Language Therapist, they will be transferred to another team for school-based support. If your child is going to an Islington mainstream school then they will be transferred to the Islington Mainstream Schools Speech and Language Therapy team. Every school in Islington has a named therapist and the early years therapist will liaise closely with the school therapist and school staff to ensure smooth handover to this new team. If your child is moving to a specialist setting, they will receive their Speech and Language Therapy in school as part of that placement. If your child will be attending a school in another borough, we will transfer to the Speech and Language Therapy service in that borough.

Further information

If you have any questions or would like to speak to the Speech and Language Therapist for pre-school children with Down's syndrome please call the early years Speech and Language Therapy Service on 020 3316 1897.

Take a look at the following websites for ideas on how to support your child's speech, language and communication skills at home

- Islington Additional Needs and Disability Service (IANDS): <https://www.whittington.nhs.uk/default.asp?c=35748>
- Tiny Happy People: <https://www.bbc.co.uk/tiny-happy-people>
- Hungry Little Minds: <https://hungrylittleminds.campaign.gov.uk/>

Speech and Language Therapy: Eating, Drinking and Swallowing

Some babies and children with Down's syndrome may show difficulties eating and drinking safely.

This may be due to:

- Low muscle tone
- Laryngomalacia
- Respiratory issues
- Gastrointestinal disorders
- Cardiac conditions
- Disrupted sensitivity to taste and texture

Children may present with coughing, choking, teary eyes, change in breathing, change in facial colour during eating and drinking. These signs may indicate aspiration (i.e. food/drink/saliva entering below the vocal folds into the trachea [airway]). This can cause chest infections and can impact on the child's health. In children with Down's syndrome who aspirate, silent aspiration (no clinical symptoms e.g. no cough response) is common so it is important to include in the case history any ongoing chest infections / number of chest infections per year, and refer to the Speech and language therapist.

If your child is having difficulties with eating and drinking they may need some help from a Speech and Language Therapist.

Referral

Your child can be referred for speech and language therapy at any time. Any health professional, e.g. GP, paediatrician, health visitor, or school SENCO involved with the child, can refer your child (with your permission and consent) to the service. Referrers need to use the Referral Form for Islington Additional Needs & Disability Services which is available at <https://www.whittington.nhs.uk/default.asp?c=26942>. Referral forms can also be requested by contacting: whh-tr.islchildrensreferrals@nhs.net

Assessment and therapy

The Speech and Language Therapist will work as part of the child's multi-disciplinary team; the multi-disciplinary team consists of Occupational therapist, Physiotherapist and Dietitian, with links to Family therapy services and other agencies as needed.

Some of the ways your speech and language therapist will support the child:

- Ongoing assessment of feeding and drinking skills
- Advice to maximise safety during feeding and drinking
- Training to caregivers and relevant education professionals to assist in the intervention process
- Working closely with other health professionals to provide strategies to help with mealtimes
- Working closely with nursery and school staff to meet eating and drinking needs

- The Speech and language therapist may also be involved in supporting the family to make the decision to use alternative feeding methods, such as via gastrostomy, or to help reintroduce oral feeding following tube-feeding
- Referral to other services

Discharge

When the child's eating and drinking needs are being met they may no longer need the additional support of a speech and language therapist.

If you have any questions, or would like to speak to a Speech and Language Therapist, please ring the Early Years Development Team on 020 3316 1676.

Further information

http://www.rcslt.org/speech_and_language_therapy/what_is_an_sl

<http://www.downs-syndrome.org.uk/for-families-and-carers/growing-up/feeding/>

Dietetics

Dietitians are responsible for working with you to help your child achieve optimal nutrition and growth as they grow older.

Babies and children with Down's syndrome may initially gain weight and grow more slowly than their peers. We use a growth chart designed by the Down's Syndrome Medical Interest Group to monitor the growth of children with Down's syndrome (www.dsmig.org.uk).

Some babies and children with Down's syndrome may have difficulties with feeding and growth due to gastrointestinal disorders such as gastrointestinal reflux, cardiac conditions or difficulty progressing with the textures of food or fluids. These babies and children may need assessment and advice to optimise oral intake, for example by fortifying food or using high energy supplements or to consider if alternative feeding such as nasogastric or gastrostomy feeding is needed.

As your child gets older they may find it harder to maintain a healthy weight. The dietitian can work with you to consider the day to day practicalities of healthy eating to be a healthy weight.

Children with Down's syndrome have a higher incidence of gastrointestinal problems like constipation and coeliac disease. There is also a higher incidence of iron deficiency anaemia and some micronutrient deficiencies. If you have any concerns about your child speak to your paediatrician who can assess and advise on treatment. A dietitian would be able to work with you to help to manage these problems.

Referral

Your child can be referred to dietetics at any time. Any health professional, e.g. GP, paediatrician, health visitor, or school SENCo involved with the child, can refer your child (with your permission and consent) to the service. Referrers need to use the Referral Form for Islington Additional Needs & Disability Services which is available

at <https://www.whittington.nhs.uk/default.asp?c=26942>. The referral form (Appendix 2) can also be requested by contacting whh-tr.islchildrensreferrals@nhs.net

Assessment

Following referral, the dietitian will gather information about your child's growth and current feeding and meet with you to talk about your child's nutrition and any difficulties you might be experiencing. The initial assessment will usually take place at home and is often with one of the other members of the multi-disciplinary team, for example, the speech and language therapist.

Treatment

The dietitian will work with you to make a nutrition plan specific to your child's needs. They will regularly review your child's growth and nutrition plan with you. Together, changes can be made to more closely meet your child's nutrition needs and to work within the family's routines.

You can meet with the dietitian in your home or in a clinic setting. Reviewing the nutrition plan can take place over the telephone or via email.

Dietitians are part of a wider multi-disciplinary team that work with you to put strategies in place to help with eating and drinking. We can be present at meetings to explain how nutrition is progressing and we can work with nursery and school staff to optimise nutrition.

Discharge

Once your child is growing steadily and you are able to continue independently with the nutrition plan your child can be discharged from dietetics. Your child's growth will continue to be monitored at medical reviews and if there are any concerns about growth or you have concerns about nutrition your child can be re-referred to the dietitian.

Early Years Education Support

The **Early Years Area SENCO Team** is part of Islington's Early Years and Childcare Service

The early years and childcare service provides a range of high-quality services for families and practitioners who support children to thrive and develop, especially in the first five years.

This is achieved by:

- ensuring the sufficiency of early years and childcare places in settings across private, voluntary and independent settings, children's centres, schools and childminders
- supporting the quality of education and care in all early years settings through monitoring and providing bespoke advice and support
- working in partnership and commissioning a range of additional support services for families and children who need them most

- providing free, impartial information, advice and guidance about services for children, young people and families in Islington through the Family Information Service

How is the Area SENCO Team organised?

An Area SENCO is linked to one of the three Bright Start Area in the borough: North, South and Central. This helps them to get to know all the other agencies in an area that might be helping the child or family.

The Early Years Area SENCO Team (EYAST) offers support and advice for children with special educational needs and disabilities in Early Years settings. We work with parents, carers, staff, and other professionals in education, health and social care. We aim to support settings so that all children can access the Foundation Stage curriculum to their full potential and make progress from their starting point.

Referral

This can be made by an early years practitioner (SENCO/Manager) via the triage referral process [EY SEND | IslingtonCS](#)

Assessment and support

The child's individual needs will be assessed and support can be delivered in a variety of ways according to the child's age and stage of development.

At first, support is likely to consist of an observation visits and meeting with the parent and the setting. A clear and transparent plan of SEN support will be developed using the graduated approach of Assess, Plan, Do and Review. A Short Team Plan (STP) will be implemented to monitor progress over time, information and targets will be reviewed termly [SEND Code of Practice January 2015.pdf \(publishing.service.gov.uk\)](#) (pp. 86-87)

For children with an Education, Health and Care Plan the review process will take place annually.

Bright Start Islington is name for services for under-5s and their families. [Find Children's Centres and Bright Start Services | Islington Directory](#) Further information on the range of Bright Start activities and services i.e. stay and play/SENsory Adventures sessions etc. can be obtained via The Family Information Service (FIS). [Islington FIS, Family Information Service | Islington Directory](#)

As the child gets older, support and advice is available to enable smooth transition across the nursery phases and school. We will continue to provide support and advice to settings and school and also offer training for practitioners. [EY Training | IslingtonCS](#)

Children will continue to receive support from the Special Educational Needs and Disability Support Services (SENDSS) during their school years.

For more information, on the Early Years Area SENCO team please visit: [Early Years Area SENCO Team | Islington Directory](#)

Educational Psychology

Preschool children with Down's syndrome are likely to be referred to the Educational Psychology Service.

How can a child be referred to the Educational Psychology Service?

If a child is attending a nursery or a children's centre, they can be referred to the Educational Psychologist (EP) by the Special Educational Needs Co-ordinator (SENCO) or Inclusion Manager. If the child is not attending an Early Years setting, a referral can be made by professionals supporting the child such as health visitors, health professionals or early support workers.

How does the service work?

The EP will visit the child and their family, usually in the nursery or at home (if they are not in an early years setting) to introduce themselves, outline their role and answer questions the parents may have.

Prior to the child starting school, the EP will be involved in monitoring and assessing the child's development and progress by:

- Observing the child in the nursery or children's centre.
- Visiting the child and parents at home if the child does not attend an early years setting.
- Meeting with the parents and nursery staff to explore strengths and concerns and problem solve jointly with parents and school staff.
- Liaising closely with the parents and other professionals involved.
- Attending short term plan meetings to regularly set and review targets where appropriate as part of the team around the child.
- Giving support and advice to adults working closely with the child regarding aspects of the child's development including social and emotional aspects of learning, child development, play, independence.
- Discussing plans for school entry including initiating and explaining Education, Health and Care needs assessment where appropriate.
- Providing educational psychology advice as part of the Education, Health and Care needs assessment process.
- Supporting transition to primary school.

When needed, the Educational Psychology service works alongside other services to plan and deliver training for EY settings and schools on supporting children with Down's syndrome in settings/schools.

For more information please visit:

http://directory.islington.gov.uk/kb5/islington/directory/service.page?id=Ldmpip3RGwo&localofferchannelnew=1_5

Islington Special Educational Needs and Disability Information Advice Service (SENDIAS)

Islington SENDIAS is free, confidential and impartial information for parents, carers, children and young people (up to 25 years). The type and range of support offered includes:

- Information regarding the local offer, local policy, SEND/ disability law from independently trained staff.
- Advice for parents, carers, children and young people on gathering, understanding and interpreting information and applying it to their own situation.
- Personalisation of personal budgets.
- Information on the local authority's processes for resolving disagreements, its complaints procedures and means of redress.
- Signposting children, young people and parents to alternative and additional sources of local and national information, advice and support.
- Individual casework and representation where needed including support in attending meetings, contributing to assessments and reviews and participating in decisions about outcomes for the child or young person.
- Support for parents and young people in managing mediation and appeals to the SEND Tribunal.
- Support for parents and young people in disagreement resolution.
- Support to parents and young people to complete SEND related benefit or grant/charity applications.

Please contact us by ringing us on 0203 031 6651 or alternatively by emailing us at islingtonSEND@family-action.org.uk

Or visit our website <https://www.family-action.org.uk/what-we-do/children-families/send/islingtonsend/>

8. Children's Social Care Early Help Support 0 – 5 years

[Early Help services for families in Islington | Islington Directory](#)

What is Early Help?

Most of the time families cope well with the demands of family life, but when circumstances change, or their usual networks of support let them down, there is help available. Islington is committed to making sure that families get support when they need it, quickly and with the minimum of fuss. This is referred to as Early Help and is available to families with children aged 0-19, to 'nip problems in the bud' before they become more serious.

Lots of families won't need a formal service and will get the help they need through advice or information, for example through The Family Information Service or their local Bright Start children's centre or local Bright Start community venue. These services are referred to as 'universal' meaning they are open to everyone.

When additional support is needed, for example with physical or mental ill health parenting or practical challenges like debt, rent arrears and unemployment, Early Help Services can step in. This support is delivered by a lead professional, usually a Family Support Worker, and is tailored to individual families with an emphasis on building skills and resilience to manage and solve problems.

Early Help thinks about the needs of the whole family and coordinates this support so there is one lead person bringing together other services as a team around the family. This means the family don't have to keep repeating their story and there is better communication between professionals.

Bright Start Islington services are for under-5s and their families living in Islington. To use services you will need to [register with Bright Start](#).

As well as childcare and early education, Bright Start Islington provides activities and services including:

- Child health clinics
- Health visiting
- [Parenting programmes](#)
- Free healthy start vitamins
- Speech and language therapy
- Breastfeeding support and infant feeding advice
- Benefits advice
- Help with finding work

Families can self-refer to the Islington Early Help Bright Start service or professionals can refer with parental consent. See web link below for more information:

Bright Start 0-5

Support for families from pregnancy until your child is five.

Family Support Surgeries, Monday-Friday between 9am-12noon: if you have a question, need some information, advice or guidance our family engagement workers are still here to talk over the phone. If lines are busy, leave a message we will get back to you when we can. If you want to speak to someone outside of these hours please send us an email.

North: BrightStartNorth@islington.gov.uk / 020 7527 8441
Central: BrightStartCentral@islington.gov.uk / 020 7527 8465
South: BrightStartSouth@islington.gov.uk / 020 7527 4089

If you are not sure which Bright Start area you are in, please contact Islington Family Information Service: 020 752 75959; fis@islington.gov.uk

[Find Children's Centres and Bright Start Services | Islington Directory](#)

What is the Local Offer?

[SEND Local Offer | Islington Directory](#)

Since September 2014 every Local Authority has been required to publish information about services they expect to be available in their area for children and young people from birth to 25 years who have Special Educational Needs and Disabilities (SEND) and also services outside of the area which they expect children and young people from their area will use. This is known as the 'Local Offer.'

The Local Offer puts all the information about education, health and care services, leisure activities and support groups in one place. It has two main purposes:

- To provide clear, comprehensive and accessible information about the support and opportunities that are available; and
- To make provision more responsive to local needs and aspirations.

The Government says the Local Offer must be developed and reviewed in partnership with children and young people, parents, and local services, including schools, colleges, health and social care agencies.

In Islington, we have worked with parent representatives from local parent forums, the SENCo Network, other service providers and children and young people to plan exactly what should be included in our Local Offer and the best way to present information.

Who is the Local Offer for?

The Local Offer is primarily designed for use by parents and children and young people with SEND. However, it will also enable practitioners and professionals to see clearly what services are available in their local area and how and when they can be accessed. All the services involved with the Local Offer have been asked to provide and maintain up-to-date information that can be easily accessed by the user. For instance, information might include who the service will suit, opening hours, accessibility, or costs. The Local Offer can also help parents find the services that are nearest to them and most suitable for their child's needs.

There is guidance to help parents find out what they need to ask practitioners and professionals and how they can be helped, with similar guidance that children and young people can access directly. The Local Offer also includes information on giving feedback and raising issues and concerns and making a complaint. The Local Offer is therefore not simply a directory of information or a list of services available.

Short Breaks Service - Islington's short break offer for the parents of disabled children and young people

[Short Breaks Service | Islington Directory \(openobjects.com\)](#)

Islington Council has a duty to provide access to short break services for the parent/carers of all disabled children aged 0-18 living in Islington. The Short Breaks statement (see link above) covers April 2022 – March 2023 and explains:

1. The range of services on offer
2. Eligibility for services
3. How to access services
4. How we develop short breaks
5. How you can shape short breaks.

We regularly review this statement and next one will published in January 2023. It is available in other formats and languages on request

The term 'short breaks' describes services that help adult parent/carers to more effectively provide care for their disabled child by providing them regular breaks so that

- they can meet the needs of other children in the family;
- they can study or take part in leisure activities themselves;
- or carry out day to day household tasks.

Short breaks give disabled children and young people the chance to take part in a wide range of activities that are fun, as well as develop new skills and experiences. They can also give the parent or carer a much-needed break.

Short breaks can take place at any time and happen either in the child's own home or within places such as early years settings, schools, youth clubs, leisure centres and adventure playgrounds. There are short breaks available after school, at the weekend or during the school holidays.

Who to contact

Telephone: 020 7527 8611

E-mail: short.breaks@islington.gov.uk

Website: [SEND Local Offer | Islington Directory \(openobjects.com\)](#)

9. Five Years to Adulthood

As your child reaches school age they will continue to have access to services depending on their needs. These vary from child to child but generally you can expect to be offered services based on current need and may find that you dip in and out of services such as speech and language therapy, dietetics, physiotherapy and occupational therapy over the coming years.

Your child's development will be considered in the context of Down's syndrome, development to date, learning levels and any other medical difficulties they have; this means that your child's care will be individualised as every child is different. This stage can be as wonderful as it is anxiety-provoking for parents as the child begins to gain some more independence starting school, and frequency of therapy-based appointments reduce or stop, with trust that the child will continue to develop within the education system. Schools and GPs work closely with children's services and therefore can and will make a referral as new needs arise.

The community paediatrician will review your child's health at regular intervals and can make appropriate onwards referrals as needed.

The following is a summary of the services available and advice on how to access these services when needed.

Community paediatrician

The community paediatrician will see your child for routine reviews annually, unless otherwise indicated. These clinic appointments will involve a review of your child's health (particularly in relation to conditions commonly associated with Down's syndrome) and development. Please see Appendix 1 for detailed information regarding what is covered in these routine paediatric reviews.

Speech and Language Therapy – school

Referral and transfers

The majority of children with Down's syndrome will need some additional help to learn to communicate. Speech and language therapists will work with you as well as other professionals involved to help your child.

If your child attends an Islington primary mainstream or special needs school your child will, usually, be transferred from the Early Years Speech and Language Therapy Team (EYSLT) to the primary school-based Speech and Language Therapy Service, with your permission. If your child has not been known to the EYSLT team, the Speech and Language Therapy Service has an open referral system which means that any professional can refer your child (with your permission) or you can do it yourself. You can find the referral form on the Whittington Health NHS Trust website: <https://www.whittington.nhs.uk/default.asp?c=26942>

Following the transfer to the Islington primary school-based Speech and Language Therapy Service, a transfer meeting will be organised with the Early Speech and

Language Therapist, the primary school-based Speech and Language Therapist and you to talk about your child's speech, language and communication needs.

Before your child starts an Islington secondary mainstream school or special needs school, the secondary school-based Speech and Language Therapist will contribute to the transition planning with your consent. Your child will then be transferred to the secondary school-based speech and language therapist once they start at the Islington secondary school.

If your child attends an out of borough secondary school we will transfer to the Speech and Language Therapy service in that borough, if appropriate.

Therapy

All children with Down's syndrome communicate in different ways and may have different speech, language and communication needs, so the support offered will be tailored to the particular needs of your child.

Our aim is to assist you, teachers and support staff to develop ways of helping your child to communicate more effectively in everyday situations.

The range of support offered will be tailored to take into account the learning environment and developmental stage of your child and may include some of the following:

- Advice for teachers and teaching assistants.
- Advice for parents and opportunities for them to observe sessions run by a speech and language therapist.
- Assessment of your child's communication skills.
- Reports summarising communication strengths and needs.
- Contribution to school support plans.
- Borough-wide and school-based training for school staff, as appropriate.
- Hands on training for school staff to carry out interventions on an individual or small group basis to meet speech, language and communication goals.
- Demonstrating activities to be used at home and within the classroom setting to support your child's communication skills and provision of resources.
- Makaton sign training for parent and carers.

We may also offer short blocks of evidence-based individual or small group therapy to achieve specific speech, language and communication goals or to address specific needs as they arise.

With your permission we will liaise with any other professionals including other Speech and Language Therapists working with your child e.g. if your child is working with an independent therapist or attending Downright Excellent.

Discharge

Children with Down's syndrome are likely to require different support at different times in their lives. We work closely with you as parents and schools to ascertain the type and level of support your child requires at various points in their schooling.

There may be times when your child's speech, language and communication needs are being met, by you as their parents and / or by their school, and they may be able to take a break from Speech and Language Therapy. Your child's speech and language therapist would discuss this with you and your child's school if it is felt this may be appropriate.

If you have any questions or would like to speak to a Speech and Language Therapist, please ring the Children's Speech and Language Therapy Service on 0207 527 5731.

Speech and Language Therapy: Eating, Drinking and Swallowing

Some children with Down's syndrome may show difficulties eating and drinking safely and may be at risk of aspiration i.e. food/drink/saliva entering below the vocal folds into the trachea (airway). Children who present with coughing, choking, teary eyes, change in breathing, wet voice quality during eating/drinking and/or ongoing chest infections may be at risk of aspiration.

Your child can be referred to the Outreach Speech and language therapy team at any time. A health professional e.g. GP, paediatrician, health visitor or school Special Educational Needs Coordinator (SENCO) can refer your child (with your permission and consent) to the service. Referrers need to use the Referral Form for Islington Additional Needs & Disability Services which is available at <https://www.whittington.nhs.uk/default.asp?c=26942>. The referral form can also be requested by contacting whh-tr.islchildrensreferrals@nhs.net

Discharge

When the child's eating and drinking needs are being met safely they may no longer need the additional support of a speech and language therapist.

Occupational Therapy & Physiotherapy

Your child's gross and fine motor skills should continue to improve, for many this is often at a slower rate than other children who do not have Down's syndrome. Your child's development can be dependent on a number of factors including other medical difficulties, opportunity, learning levels, child's interests, their own individualised rate of development and whether or not they are in education.

It is useful to think about your child's motor development in terms of their progress in learning new everyday life skills. In order to support this development your child is likely to need a lot of practice and a graded approach, which means starting easy, or learning the first step, and providing a lot of encouragement and positive reinforcement to ensure your child has mastered the initial step before moving on to the next. Children with Down's Syndrome may take longer to learn new skills in comparison to other children and often be limited by factors typical to children with Down's syndrome such as shorter fingers (making fine motor skills more difficult).

If your child is not making any progress towards their goal this is when professional advice through a Physiotherapist or Occupational Therapist can be useful.

Children with Down's Syndrome often have low tone (i.e. they may have weak muscles and supporting structures around their joints). This is something that will need ongoing management throughout their lifespan with the emphasis on strengthening activities to improve and maintain muscle strength and stability. This is achieved through everyday activities of daily living (such as playing, cycling, climbing, running, opening and closing containers, scissor skills etc.), through organised leisure activities (such as drama, swimming etc.) or through prescribed exercises which can be via a maintenance programme incorporated into daily and weekly activities so your child may not have regular therapy input.

The more integrated and motivating strength and movement activities are to everyday life, the greater the impact and lasting effects on everyday functioning; this is why an emphasis on participation within the classroom, playground and out of school activities are seen as important and often more important than ongoing therapy programmes.

If your child does need a therapy programme this will be goals based with the aim to progress to school based or community-based activities.

Physiotherapy and Occupational Therapy input is typically episodic and may be in the form of consultation, individualised assessment, therapy programme and/or group work depending on the need and identified goal for the episode of care. If you are concerned about your child's gross or fine motor skills and feel that they are not making progress despite working on these skills with your child you can ask your GP, school nurse, SENCO or any health professional to make a referral to the service.

Referrals to Physiotherapy are accepted if your child is having functional difficulty with walking or running, stair mobility, accessing playground equipment and/or experiencing pain. Your child will be assessed by a Physiotherapist and a treatment plan based on goals will be discussed and agreed. This discussion could involve general advice, onward referrals or a block of therapy. A block of therapy may be offered by a physiotherapist or a physiotherapy assistant under the supervision of a physiotherapist. This block could also include a referral to an exercise group. Once goals are achieved your child will be discharged with a maintenance programme and the option of re-referral in the future as needed.

Referrals to Occupational Therapy are accepted if there are two or more functional areas where your child is not making progress towards despite significant input from home and school. This means that your child is not making progress with self-help and independence skills (such as dressing, using scissors, eating with fork or spoon, etc.) despite being interested in the activity and having lots of opportunity to practice.

The Occupational Therapy Service also offers monthly drop-in clinics which you and your child can attend without having a referral. Please phone 0203 316 1997 to find the date of the next occupational therapy drop-in clinic.

Dietetics

Dietitians are responsible for working with you to help your child achieve optimal nutrition and growth as they grow older.

Children with Down's syndrome should continue to have their growth monitored regularly. We use a growth chart designed by the Down's syndrome Medical Interest Group to monitor the growth of children with Down's syndrome (www.dsmig.org.uk).

As your child gets older they may find it harder to maintain a healthy weight. The dietitian can work with you to consider the day-to-day practicalities of healthy eating to be a healthy weight. Children who are 5-18 years can be referred to the Healthy Living Practitioner. This service is available to children who have an Islington GP, are overweight (**on or above the 91st BMI percentile**) or there are significant concerns about weight gain or diet / exercise. Any health care professional can refer your child to the Healthy Living Practitioner with your permission. Referral forms can be requested from whh-tr.sn-islhealthliving@nhs.net.

Some children with Down's syndrome will continue to need gastrostomy feeding. The dietitian will work with you and other health care professionals like the speech and language therapists and Children's Community Nurses to review and modify the gastrostomy feeding plan to meet your child's needs.

Referral

Your child can be referred to dietetics at any time. Any health professional, e.g. GP, paediatrician, health visitor, or school SENCO involved with the child, can refer your child (with your permission and consent) to the service. Referrers need to use the Referral Form for Islington Additional Needs & Disability Services which is available at <https://www.whittington.nhs.uk/default.asp?c=26942>. The referral form (Appendix 2) can also be requested by contacting whh-tr.islchildrensreferrals@nhs.net

Assessment

Following referral, the dietitian will gather information about your child's growth and meet with you to talk about your child's nutrition and any difficulties you might be experiencing. The initial assessment can take place at home or in a clinic setting.

Treatment

The dietitian will work with you to make a nutrition plan specific to your child's needs. A dietitian will regularly review your child's growth and nutrition plan with you. Together changes can be made to more closely meet your child's nutrition needs and to work within the family's routines.

You can meet with the dietitian in your home or in a clinic setting. Often reviewing of the nutrition plan can take place over the telephone or via email.

Dietitians are part of a wider multi-disciplinary team that work with you to put strategies in place to help with eating and drinking. We can be present at meetings to explain how nutrition is progressing and we can work with school staff to optimise nutrition.

Discharge

Once your child is growing steadily and you are able to continue independently with the nutrition plan your child can be discharged from dietetics. Your child's growth will continue to be monitored at medical reviews and if there are any concerns about growth or you have concerns about nutrition your child can be re-referred to the dietitian.



Educational Health and Care Plans

Educational Health and Care Plans are needs based and are sometimes applied for when the school feel that they are not able to meet the child's needs without additional funding or support. If you feel that your child needs an Educational Health and Care Plan please discuss this with the Special Education Needs Co-ordinator (SENCO) at your child's school. The Islington SEND Community Support Service also provides support and advice to parents on this process, more information is available at www.family-action.org.uk.

Educational Psychology

Educational psychologists will work with you and your child as well as the school and other professionals to support their learning, wellbeing and development within the school environment. Their aim is to promote access and inclusion by applying psychology and working in partnership with schools, children and young people, their families and other professionals involved.

How can a child be referred to the Educational Psychology Service?

All Islington schools have a link Educational Psychologist. Children can be referred to the Educational Psychologist (EP) with your consent by the Special Educational Needs Co-ordinator (SENCo) or Inclusion Manager within your child's school.

The range of support offered may include:

- Meet with staff, parents/carers to jointly explore strengths and needs and collaboratively problem solve around the concerns.
- Observation of the pupil in the learning environment.
- Assessments of the child's strengths and areas of need, including psychological assessment and advice as part of the Education, Health and Care needs assessment if needed.
- Advice and support for school staff including training.
- Liaising closely with the parents and other professionals involved.
- Work with parents/carer to support their children's learning, development and wellbeing.
- Support around transition time, for example from Primary to Secondary school, to ensure successful transition.

For more information please visit:

http://directory.islington.gov.uk/kb5/islington/directory/service.page?id=Ldmpip3RGwo&localofferchannelnew=1_5

Supported employment / Apprenticeships

Supported Internships are personalised study programmes based primarily at an employer's premises. They are designed to better enable young people with severe learning difficulties and/or disabilities to achieve sustainable paid employment by equipping them with the skills they need for the workplace. For more information on Supported Internships for Young People with SEND click here [Supported Internships for Young People with SEND | Islington Directory](#)

Child and adolescent mental health services (CAMHS)

Child and Adolescent Mental Health Services (CAMHS) aim to support and help with children and young people age 0-18 and their families who are experiencing moderate to severe emotional and mental health problems. CAMHS is a multi-disciplinary team of mental health professionals (including Clinical Psychologists, Psychiatrists, Family Therapists and Child Psychotherapists). The team works closely with colleagues in children's services (Education, Disabled Children's Team, Speech and Language and Occupational Therapists and Paediatrics as well as Early Support) to support also children and young people with Down's syndrome from birth to 18 years. We provide specialist assessment, both comprehensive and multidisciplinary including diagnosis; therapy, including individual, family and group work. We also offer an in-patient care and treatment to children and young people.

We can help with:

- Emotional difficulties such as anxiety, depression, phobias, obsessive compulsive disorder and school refusal

- Behavioural difficulties, such as inattention, impulsivity, defiance or challenging, aggressive behaviour, obsessive behaviours, sexualised behaviours
- Severe psychiatric illness such as psychosis.
- Self-harm or risk of self-harm (please note that all those who have taken overdoses should be taken to the local A& E department)
- Trauma including post-traumatic stress disorder (PTSD) and trauma following abuse.
- Emotional difficulties associated with physical health problems e.g. soiling, sleeping, eating
- Developmental/ neurodevelopmental difficulties: assessment and effective solutions to the difficulties raised by Autism, Attention Deficit Hyperactivity Disorder and Tics.

Like our Speech and Language Therapy and Occupational Therapy colleagues, we have found that families might 'dip in and out' of their relationships with CAHMS, depending on their identified needs and what else might be going on for parents or children/young people themselves. We often work through parents or offer training and consultation to teaching staff in Islington mainstream and specialist schools (particularly Samuel Rhodes Primary and Secondary) where there are concerns about behaviour, routines or transitions to primary or secondary school. We have CAMHS clinicians located in each of the primary, secondary and special schools in Islington.

We receive referrals from parents, GPs, teaching staff and other professionals on behalf of young people who may be struggling with managing more difficult feelings such as low mood, behaviour and anxiety. We offer assessments of learning if there are issues impacting on emotional well-being or mental health and parenting courses to parents of primary school- aged children, who are struggling with managing behaviours that challenge at home. We might work with the whole family when they are struggling with issues related to diagnosis – especially as different feelings can emerge for family members and young people themselves at particular stages in their life cycle. We also offer functional assessments of behaviour and adapted interventions to suit children and young people with Down's syndrome, who may have associated mental health challenges.

How to refer:

If you know a child or young person that requires mental health support or intervention and you would like to refer for a service, please follow this link <https://www.islington.gov.uk/children-and-families/worried-about-a-child> and complete the referral form which will be screened by the Islington Social, Emotional and Mental Health Intake team (which includes CAMHS services). Alternatively, you can call 020 7527 3355 to speak to the duty clinician, (phones are staffed 9-5 Monday-Friday) if you would like to enquire about referrals or relevant services.

Please refer to the Islington CAMHS website <https://www.whittington.nhs.uk/default.asp?c=27127> for a short video about what to expect in a first appointment and other information about the services.

Please also see the leaflet link here for adapted materials to share with young people themselves, who have Down's syndrome and want some support with their mental health <https://www.mentalhealth.org.uk/sites/default/files/feeling-down-guide.pdf>

Growing Together

Growing Together is an innovative partnership between iCope (primary care adult mental health service) and Islington CAMHS. The team provides psychological intervention to parents with primary care level mental health issues and their children aged one to five, who also require psychological intervention. This might be problems with emotions, behaviours and or relationships. We welcome families from diverse backgrounds and cultures and individuals who identify as LGBTQ+. Families need to have a GP within Islington.

The service offers a range of interventions and tailors support to each individual family, with the aim of improving both parent and child wellbeing. This can include therapy with parents to address adult mental health issues like depression and anxiety, family therapy, couple, co-parenting sessions and parent-infant psychotherapy. Parent groups and workshops are also offered, as well as consultation with the network around the family. Our team is made up of Clinical Psychologists, Child Psychotherapists and Family Therapists.

10. Children's Social Care

Early Help Support 5 - 19 years

Bright Futures, Early Help 5-19 (school-age to 19 years)

[Bright Futures, Early Help 5-19 \(school-age to 19 years\) | Islington Directory](#)

We support families with school-aged children up to 19 years old. We're here for you, in your community when you need us.

What we can help with?

We know that being a parent is not always easy and that all families need extra help at some stage as children grow up. This might be because your housing situation is difficult or you are hoping to get into work or training. A relationship may have broken down or someone close to you has gone to prison. Your teenager's behaviour might be challenging at home or at school. You may have growing debts or you may be at risk of losing your home.

How do we work?

You'll work with the same trained family worker every time you see us, at your home or in our community locations, in the day or in the evening.

What do we do?

We'll ask you what you and your family need and plan what we need to do together. We will bring together other services to work with us depending on what you need. For example, this might be housing, schools, prison, probation, young people's services and Jobcentre Plus. We also offer parenting support and community events.

- Families can make referrals over the phone on 020 7527 4343.
- All professionals wanting to make a referral to Families First, are required to complete the Islington CSCT referral form and to email it by secure email to csctreferrals@islington.gov.uk.

Who to contact

Telephone: 020 7527 4343

E-mail: Early.Help@islington.gov.uk

Children's Social Care 0 – 25 years

Disabled Children's Service (DCS)

[Disabled Children's Service \(DCS\) | Islington Directory](#)

Islington Council Disabled Children's Service is a multi-agency partnership of services offering information, advice, assessment, intervention and support to children with severe and complex Disability needs who may receive Special

Educational Needs (SEN) Support Plan in School or have an Education Health Care Plan (EHCP).

We provide services for Disabled Children and Young People aged 0-18 (social care) and 0-19 (health) and young adults with Disabilities from 14 - 25 years through the [Progression to Adulthood \(PFA\) Transition Team](#) and the Islington Learning Disabilities Partnership (ILDP) in adult social care.

The [DCS Threshold Statement](#) sets out the eligibility criteria for children/young people to receive a service from the Disabled Children's Service.

There are seven social care teams in the Islington Disabled Children's Service:

- Disabled Children's Social Work Team (DCT)
- Disabled Children's Family Support and Reviewing Team (FSRT)
- Disabled Children's Family Outreach Team (FOT)
- Disabled Children's Direct Payments Team (DPT)
- Disabled Children's Consultation and Advice Team (DCCATS)
- Disabled Children's Transforming Care, Prevention and Support Service (TCaPS)
- Progression to Adulthood (PFA) Transitions Team and Learning Disabilities Partnership

Disabled Children's Social Work Team (DCT)

The Disabled Children's Team is part of the [Disabled Children's Service](#) at the Northern Health Centre.

The team works with Disabled Children with severe and complex needs to provide statutory social work services as set out in National and Departmental legislative frameworks.

The [DCS Threshold Statement](#) sets out the eligibility criteria for Children/Young people to receive a service from the Disabled Children's Social Work Team.

The team completes child in need (CIN) assessments of disabled children and their families, works with families to address safeguarding concerns, responds to urgent crisis situations and provides support to children who are looked after. If a child's assessment identifies a need for additional support such as a Disabled Children's Personal Budget, social workers will work with families to complete a child in need (CIN) Support Plan and Personal Budget.

Once a CIN Support Plan and Personal Budget is agreed by the Islington [Education, Health and Care Management Board \(EHCMB\)](#) and if there are no safeguarding concerns and there is no ongoing role for a social worker the Plan will step down to the Family Support and Reviewing Team (FSRT) who will complete an annual Child in Need Review Meeting and update the plan every year as required.

Referrals are accepted from parents/carers, public, teachers, doctors and other professionals as well as from the voluntary sector.

Support from a Social Worker

If your Child and family needs more support than is available through Early Help Services, Bright Start or the Local Offer you will need an assessment by a social worker. As part of the assessment the social worker will visit you to gather information about your family and your Child's disability and support needs. They will also talk with other professionals who are working with your Child and visit your Child at school or nursery and other settings (e.g. after school club) as well as at home.

The assessment will also consider your needs as a parent carer and the needs of any siblings in the family. If the assessment indicates that you do need additional support, the social worker will complete a Supported Assessment Questionnaire (SAQ), talk to you about a support plan and advise you about the options of managing this plan. This could include the option of a Personal Budget which is a way of giving you more choice and control over the support you choose.

Referrals are generally made by a professional who is working with you and your child but you can also refer yourself for a social work assessment. Where there are any concerns about the health and wellbeing of a child, this will always take the form of a social work assessment.

For further information and support contact the Disabled Children's Social Work Team (DCT).

Who to contact:

Telephone: 020 7527 3366

E-mail: disabledchildren.team@islington.gov.uk

Disabled Children's Family Support and Reviewing Team (FSRT)

The Disabled Children's Family Support and Reviewing Team (FSRT) is based at the Lough Road Centre. All the children accessing this service will have a Child in Need (CIN) support plan and Personal Budget (PB) in place following a Children and Family single assessment of their needs undertaken by a social worker. Once a child's plan is agreed by the Islington Education, Health and Care Management Board, if there are no safeguarding concerns and no ongoing role for a social worker, cases step down to this team.

Their main role of the Family Support and Reviewing Practitioner (FSRP) is to review your child's Child in Need Support Plan on an annual basis and to act as a point of contact for non-urgent issues and we aim to visit children either at home or at school every 6 months. This is to ensure the package of support continues to meet the needs of your disabled child and your family and focus resources on the best ways to achieve positive outcomes. Wherever possible these reviews will be part of your child's annual education, health and care plan review arranged by your child's school. The FSRT will also offer individualised family support to a small number of

families requiring a lead professional, this role is however limited; in most cases the FSRP will only be able to provide advice and signposting to other services.

Who to contact:

Telephone: 020 7527 2095 or 020 7527 7263

E-mail: fsrt@islington.gov.uk

Disabled Children's Family Outreach Team (FOT)

The Family Outreach Team in Islington is a new service that was launched in October 2020. Our team works in partnership with parents, disabled young people, schools and professionals to help support families with a child or young person with a disability where there are escalating challenging behaviours which could be supported by providing a three month programme of outreach support within the home and community.

Our small team of Family Outreach Practitioners will be using a range of evidence based interventions to work in partnership with the family and lead professional to identify goals and work together to improve their quality of life.

Our practitioners use motivational interviewing, positive behaviour support and trauma informed practice to ensure best practice.

Our service aims to support children that meet the following criteria:

- Young children with a diagnosis of a Learning Disability (LD) or Autistic Spectrum Condition (ASC) who are presenting with challenging behaviour at home which appears to be escalating.

Or

- Young People who have a diagnosis of LD or ASC and a secondary Social, Emotional and Mental Health (SEMH) diagnosis who are presenting with Challenging behaviour exuberated by adolescence.

Who to contact:

Telephone: 020 7527 2095 or 0207 527 7263

E-mail: loughroadmin@islington.gov.uk

Who is this service for?

Disabled Children and Young People aged 5 - 18 years and their families.

Can I refer myself?

No

How to refer or apply

Referrals can only be made by professionals to the [Disabled Children's Social Work Team](#) or directly to the Family Outreach Team via Telephone or email.

Disabled Children's Direct Payments Team (DPT)

The Disabled Children's Direct Payments Team is based at the Lough Rd Centre.

The team works closely with the **Disabled Children's Social Work Team (DCT)** and the **Disabled Children's Family Support and Reviewing Team (FSRT)** to set up child in need Support Plans and Personal Budgets for Children with Disabilities.

The Direct Payments Team works alongside families and professionals using a strength based approach to implement individualised support plans for Disabled children and young people to meet assessed needs.

The team also helps to implement personal budgets by setting up direct payments for social care, health and education.

Support is provided by 2 Support Planners based in the Disabled Children Social Work Team and a Direct Payments Advisor based at Lough Road Centre. There is also a Direct Payments Manager, Finance Monitoring Officer and Finance officer who oversee invoicing, issuing Pre-Paid Cards and ensuring that Personal Budgets and Direct payments are monitored.

Information and advice for professionals and families to manage personal budgets:

- Information about Children with Disabilities Personal Budgets
- Information and advice about Children with Disabilities Direct Payment arrangements
- Advice with recruiting and managing Direct Payment Personal Assistants and Support Workers for Children with Disabilities
- Support and advice with Personal Budget financial monitoring.

Who to contact:

Telephone:020 7527 7263

E-mail:LRCDirectPayments@islington.gov.uk

Disabled Children's Consultation and Advice Team (DCCAT)

DCCAT are based at the Lough Road Centre

How do we work?

The Disabled Children's Consultation and Advice Team does not case hold, but are a small team of three advisors with a wide range of experience, skills and knowledge. We can upskill professionals in universal and targeted settings, including family support workers, nursery staff, and any professional working directly with children, young people who already have diagnosed disability or are currently awaiting a social communication assessment for Autism from birth to 17 years (and their families). We provide webinar training and workshops throughout the year which can be accessed by all professionals.

Feedback and learning from the training webinars can be explored in case discussions following the workshops and some individual advice and consultation may be provided through surgeries throughout the year.

What do we do?

The advisors work to equip professionals with strategies and resources to be confident in working directly with Disabled children and their families and carers.

What can we help with?

We can help to identify resources and give guidance on practical strategies like creating social stories, using visual timetables and embedding consistent routines. This includes individual tailored plans meeting the needs of the child and family.

How to refer or apply:

Referrals are made directly only by professionals

Disabled Children's Transforming Care, Prevention and Support Service (TCAPS)

Transforming Care, Prevention and Support (TCAPS) is an outreach service managed by Islington which operates in Islington, Camden and Haringey. The overall aim of the TCAPS service is prevent families from going into crisis, and ultimately to reduce Tier 4 hospital admissions and residential placements for Children with Disabilities who present with challenging behaviour by delivering a bespoke a six month outreach programme within the home and community. This is linked to the aims of the Transforming Care programme, led by NHS England.

Families that TCAPS can support?

Families who have a child/young person with:

- Diagnosis of Autistic Spectrum Condition (ASC) with Social Emotional Mental Health (SEMH) needs and/or behaviour that challenges.
- Learning Disability (LD) with Social Emotional Mental Health (SEMH) needs and/or behaviour that challenges.

We hope that the outcomes achieved will show an increase in quality of life for the children/young people and their families, increased confidence and resilience and decreased need for statutory social work services.

How we work?

To achieve these outcomes, the TCAPS Key workers will use the positive behaviour approach to understand behaviours and how best to manage over a six month programme of outreach support. This service is very child/family centred, and so will be flexible in order to meet the needs of each family.

Who to contact:

Telephone: 020 7527 2095 or 0207 527 7263

E-mail: loughroadmin@islington.gov.uk

Who is this service for?

Disabled Children and Young People aged 5 - 18 years and their families.

Can I refer myself?

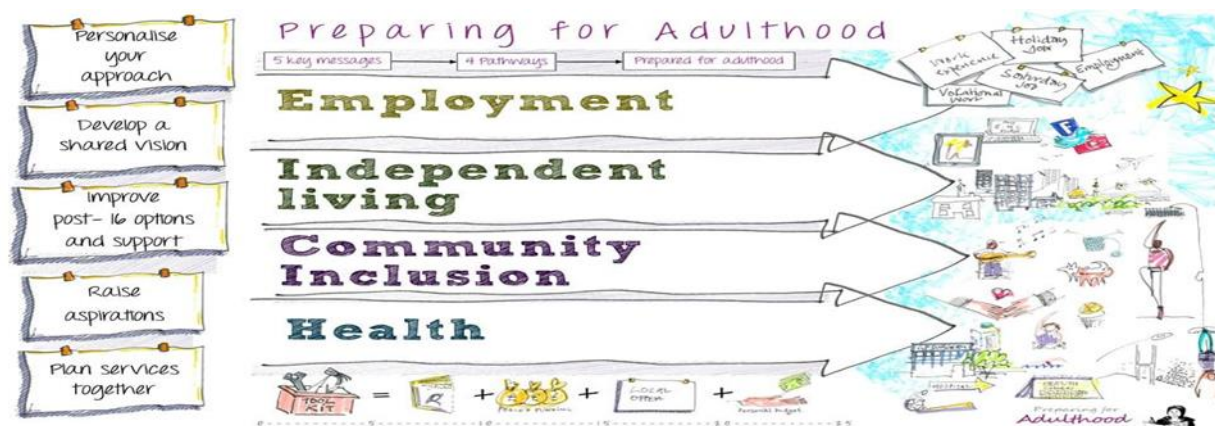
No

How to refer or apply

Referrals can only be made by professionals to the [Disabled Children's Social Work Team](#) or directly to the Family Outreach Team via Telephone or email.

11. Transition and Progression to Adulthood

[What do we mean by Preparing for Adulthood? | Islington Directory](#)



Transition and Progression to Adulthood support comes at a time when a lot of change can take place in a young person’s life. It can mean changes to the care and support they receive from education, health and social care or involvement with agencies new to the young person like housing and further education.

In Islington, we like to start planning these changes with you and your young person as soon as we can so that the moves are as smooth as possible. We also know that careful transition planning that fully involves your young person right from the start will give them the chance to learn or strengthen new skills (for example decision making and resilience). All of this will start when we look at your young person’s Education, Health and Care Plan at the Annual Review in Year 9. Everyone working with you must make sure that the plan reflects your young person’s wishes and aspirations and ensure that they are prepared as possible for adult life.

The Transition Worker will ensure that your young person is settled into adult services before leaving children’s services.

Transition to adult health services

Your young person’s community paediatrician will ensure that referrals are made to the adult health teams that your child requires.

They will also ensure that your GP is kept fully up to date with these changes. After your young person turns 18, their GP will be the main health professional coordinating your young person’s health services.

Your young person will be eligible for an annual health checks provided by your GP. These health checks are available from the age of 14 years. The Down’s syndrome Association have developed a ‘Health book’ which the young person with Down syndrome can take to their annual health check. For more information, see

<https://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/annual-health-checks/>

What happens between 18 to 25 years?

From Year 11, the Local Authority will ensure the Education, Health and Care Plan is reviewed every year to make sure that it is still meeting your young person's needs, e.g., making sure that the plan reflects any changes in their life like a new personal interest or a desire to find a job.

The Local Authority can only cease an Education, Health and Care Plan if it thinks it is no longer necessary e.g. special educational provision is no longer needed as the educational outcomes set out in the plan have been achieved.

When a Young Adult is close to finishing education, we will use the final annual review to agree the support needed to help them engage with services after they leave education.

The Transition Social Worker / SEND Keyworker will continue to work with you until you leave full time education. The age that happens will vary, but these teams do not work with anyone over the age of 25 years, so ongoing adult social care support will be provided by the Locality Adult Social Care Teams.

Adult Social Care

The Transition Team will automatically work with Islington Young People 14 years and older who attend The Bridge School, Richard Cloudesley School or Samuel Rhodes School with a global learning disability, Profound Autism Diagnosis and young people with a significant physical disability. Young people can also be referred directly to the team. Referral is by assessment and eligibility will be determined from this.

The Transition Team is a team of Social Workers based within Islington Adult Social Care and the Islington Adult Learning Disabilities Partnership. The team will support children and parents to receive the appropriate support from Adult Services at the relevant time. Your child will be allocated a worker close to their seventeenth birthday. However, we offer coffee mornings for parents of children aged between 14-17yrs; this provides an opportunity to answer your questions at an earlier stage in the process (please ask your schools about these).

Transition Assessment

Once your young person is 17 years of age their social care needs will be considered and assessed under the Care Act 2014.

Local Authorities must carry out a **Transition Assessment** if a Young Person is likely to have care and support needs after turning 18 years. This assessment will help design the right care and support plan.

The Transition Social Worker will provide you with a guidance document 'Preparing for Adulthood', which offers a detail explanation and timescales of the process.

Who to contact

Telephone: 020 7527 3108

E-mail: transition.team@islington.gov.uk

Team Manager – Tony Macisaac

Email: Macisaac@Islington.gov.uk

Telephone: 0207 527 4431



12. Other teams who you might work with on your journey

Additional support

Islington SEND Community Support Service can provide a range of information and support to parents and carers in the borough and can be approached directly by families or professionals.

Contact: 0203 031 6651/6652 or islingtontsend@family-action.org.uk

Short Breaks

The Short Breaks Service can consider requests for additional support without necessarily the need for an assessment, and offers a range of breaks and activities including after school clubs, holiday play schemes and outreach services.

For details of Islington's Local Offer, please see the Local Offer web pages.

www.islington.gov.uk/children-and-families/send-local-offer

Short breaks give disabled children and young people the chance to take part in a wide range of activities that are fun, as well as develop new skills and experiences. They can also give the parent or carer a much-needed break.

Short breaks can take place at any time and happen either in the child's own home or within places such as early years settings, schools, youth clubs, leisure centres and adventure playgrounds. There are short breaks available after school, at the weekend or during the school holidays.

For further information about Short Breaks for children with severe and complex needs:

http://directory.islington.gov.uk/kb5/islington/directory/advice.page?id=lujw_X1WJyl

Contact: 0207 527 8611 or Short.Breaks@islington.gov.uk

Flexible Breaks Fund

The Flexible Breaks Fund pays for carers to have a break from their caring role. It's for parents and carers who provide unpaid care or support to an Islington resident aged 17 and under.

The person they care for could be their child, a relative, friend or neighbour who can't manage without their support. This could be because of illness or emotional or behavioural issues.

The carer must live in the same household as the person being cared for.

How to apply

Download the application form from 'useful documents' below. The form must be endorsed by a professional.

More information

Phone: 0207 527 7116

Email: flexiblebreaks@islington.gov.uk

Help for young carers

This scheme is not available to young carers, but we have special support for carers under 25.

Phone: 020 7272 6933

Email: islington.youngcarers@family-action.org.uk

Centre 404, Charity for people with learning disabilities and/or autism

Centre 404 gives information and advice on disability related benefits and support families in getting the right benefits at the right time. They will give you information and support around welfare benefits and disability benefits, direct payments and personal budgets.

Disability Benefits

- Disability Living Allowance (DLA) for children may help with the extra costs of looking after a child who is under 16 and has difficulties walking or needs much more looking after than a child of the same age who does not have a disability
- Personal Independence Payment (PIP) for people aged 16 to 64 and need help with some of the extra costs caused by long term ill-health or disability.

Contact: Supporting Families Service on 020 7697 1336 or family@centre404.org.uk

Website: <http://centre404.org.uk/our-services/support-for-families-2/>

Centre 404 also offers fun regular weekly activity groups, holiday play schemes and outreach support for children, young people and adults.

Website link: <http://centre404.org.uk/our-services/groups-and-activities-3/>

The Islington Parents Forum

The Islington Parents Forum is a group for parents of children with Special Educational Needs and Disabilities (SEND) who live in Islington. This important meeting takes place every two months and is a chance for you to discuss matters that are important to you, participate in consultations and comment on developments in local and national disability services. It is an active group which has the specific aim to provide service providers with the views and concerns of their service user group.

Contact: Supporting Families Service at Centre 404 on 020 7697 1336 or family@centre404.org.uk

Website link: <http://centre404.org.uk/engagement-have-your-voice-heard/>

Facebook Page: [@IslingtonParentsForum](https://www.facebook.com/IslingtonParentsForum)

The Bridge Service

[The Bridge Service | Islington Directory \(openobjects.com\)](#)

The Bridge is a sexual health service for anyone over 16 with a learning disability living in Islington or Camden. The service offers:

- Advice and support on sex and relationships
- Free contraception and condoms
- Tests and treatment for sexually transmitted infections (STIs) and HIV
- Friendly healthcare staff
- Appointments with a doctor if needed
- Pregnancy advice and contraception help
- LGBT friendly service
- A safe place to report any worries or concerns
- A private and confidential service

Who to contact

Telephone: 020 3317 5252 - to book an appointment (ask for the Bridge Service)
0773 826 1323 - for advice or to find out more

Location:

Archway Sexual Health Clinic
689 Holloway Road
London N19 5SE

13. Sources of Information

- **Down's syndrome association:** www.downs-syndrome.org.uk Helpline: 0333 1212300 (10am-4pm) or Email: info@downs-syndrome.org.uk
- **Down's syndrome Medical Interest Group:** www.dsmig.org.uk supports health care professionals working with children with Down's syndrome.
- **Down's syndrome education international:** www.downsed.org supports families, health care professionals, researchers and teachers
- **Down heart group:** www.dhg.org.uk a charity offering support and information relating to heart conditions associated with Down's syndrome
- **Downright Excellent:** www.downrightexcellent.org provides highly specialist and syndrome specific therapies and quality play experiences for children with Down's syndrome aged 0-16 and their siblings, plus education and support for parents/ carers & associated professionals e.g. nursery & school staff.
- **Islington SENDIAS (Family Action):** impartial support, advice and information on Special Educational Needs and Disability: <https://www.family-action.org.uk/what-we-do/children-families/.../islingtonsend/>
- **Positive about Down Syndrome** – a parent support group by parents for parents and parents-to-be: <https://positiveaboutdownsyndrome.co.uk/>
- **Afasic:** support service for people who have problems talking or understanding language and their families. Ring the Afasic Parents' Helpline on 0300 666 9410 during opening hours – Monday & Wednesday: 10.30am to 4.00pm. Web link: <https://www.afasic.org.uk/help-for-your-child/not-talking/afasic-helpline/>

We are always keen for parents to be involved in the development of our services. If you would like to be involved in future development, please let us know.

If you are not satisfied with the support that you are receiving from health services or would like further help then please discuss with professionals working with you in the first instance, or you can contact:

Lesley Platts, Designated Clinical Officer Islington
l.platts@nhs.net

or

Patient Advice and Liaison Service, Whittington Health: 020 7288 5551 / whh-tr.whitthealthPALS@nhs.net

Appendix 1: Paediatric checklist

BIRTH	<ul style="list-style-type: none"> • <i>Karyotype</i> • <i>ECHO <6 weeks</i> • <i>FBC & film</i> • <i>TFTs</i> 	<ul style="list-style-type: none"> • <i>Vision (cataract)</i> • <i>Universal hearing</i> • <i>Guthrie screening test</i>
6 MONTHS	<ul style="list-style-type: none"> • Formal audiology assessment by 12 months <input type="checkbox"/> • Ensure health surveillance at birth (see above) is complete <input type="checkbox"/> 	
1 YEAR	<ul style="list-style-type: none"> • Blood tests: FBC, ferritin, TFTs, TPO antibodies, coeliac screen <input type="checkbox"/> <p><i>If TFTs abnormal or TPO raised, will need to repeat more frequently- otherwise every year</i></p> <ul style="list-style-type: none"> • Immunology 1m after 12m immunisations: Immunoglobulins, functional antibodies (i.e tetanus and Hib, Prevenar antibodies), lymphocyte subsets - <input type="checkbox"/> • Ophthalmology assessment by 18 months <input type="checkbox"/> • Annual dental review <input type="checkbox"/> 	
2 YEARS	<ul style="list-style-type: none"> • Blood tests: TFTs, TPO antibodies, FBC, ferritin <input type="checkbox"/> • Local Educational Authority notification <input type="checkbox"/> • Annual hearing check <input type="checkbox"/> • Annual vision check • Annual dental review <input type="checkbox"/> • Advise need for single dose of Pneumovax II between 2-5years <input type="checkbox"/> 	
3 YEARS	<ul style="list-style-type: none"> • Blood tests: FBC, ferritin, TSH, T4, TPO antibodies <input type="checkbox"/> • Annual hearing check <input type="checkbox"/> • Annual vision check <input type="checkbox"/> 	

	<ul style="list-style-type: none"> • Annual dental review <input type="checkbox"/> • Advise need for single dose of pneumovax II between 2-5years (if not had) <input type="checkbox"/>
4 YEARS	<ul style="list-style-type: none"> • Blood tests: FBC, ferritin, TSH, T4, TPO antibodies <input type="checkbox"/> • Annual dental review <input type="checkbox"/> • Annual hearing check <input type="checkbox"/> • Advise need for single dose of pneumovax II between 2-5years (if not had) <input type="checkbox"/>
5 YEARS	<ul style="list-style-type: none"> • Blood tests: FBC, ferritin, TSH, T4, TPO antibodies <input type="checkbox"/> • Annual hearing check <input type="checkbox"/> • Annual vision check <input type="checkbox"/> • Annual dental review <input type="checkbox"/>
6-14 YEARS	<ul style="list-style-type: none"> • Blood tests: Annual FBC, TFTs, TPO antibodies <input type="checkbox"/> • 2 yearly hearing check <input type="checkbox"/> • 2 yearly vision check <input type="checkbox"/> • Annual dental review <input type="checkbox"/>
ADULTHOOD	<ul style="list-style-type: none"> • Single ECHO <input type="checkbox"/>
<i>Atlanto-axial instability and Sports advice</i>	<p>In asymptomatic individuals sports do not need to be avoided. However for gymnastics and trampolining the British Gymnastic Association suggests the following:</p> <ul style="list-style-type: none"> • <i>Parent/Guardian's consent is obtained (under 18's)</i> • <i>There is no evidence of progressive myopathy in the person concerned</i> • <i>That neck flexion to allow the chin to rest on the chest is possible.</i> • <i>That the person has good head/neck muscular control.</i>

Additional investigations (e.g. coeliac screen) should be performed at any review depending on the history and examination findings.

Appendix 2: Referral Form for Islington Additional Needs Health Services

**REFERRAL FORM FOR ISLINGTON ADDITIONAL NEEDS AND
DISABILITY SERVICES (IANDS)**

Is this referral for (please tick):

Speech and Language Therapy (SLT)

Occupational Therapy (OT)

Physiotherapy (PT)

Community Paediatrics

Speech and Language therapy:

-Eating and drinking difficulties/swallow safety

Dietetics

Social Communication Team:

-assessment and intervention for autism spectrum disorder
0-5 yrs

(For assessment of autism spectrum disorder 5-18 yrs refer to CAMHS)

Please note that we can only accept referrals with complete information. If information is missing, we may have to return the form for completion before an appointment can be offered. Please attach any relevant reports / documentation to support the referral.

Child's name.....Male/female NHS No.....

Date of birth..... Parent/carer name.....

Address.....

Email Postcode.....

Home telephone..... Mobile telephone.....

Nursery/children's centre/school (if known).....

GP..... Address.....

Health visitor..... Address.....

Languages spoken Ethnicity Interpreter needed Yes No

Current family and home situation (if known):

Who lives at home

Significant others in child's life.....
 Are there any known risks in visiting the home.....

 Is this child Looked After? Yes No

Other professionals involved (please tick all that apply):

Paediatrician: Name.....Tel.....
 Clinical psychologist/CAMHS: Name.....Tel.....
 Educational Psychologist: Name.....Tel.....
 Social worker: Name.....Tel.....
 Family support worker: Name.....Tel.....
 Audiology/ENT: Name.....Tel.....
 Hospital Team Name.....Tel.....
 Others (please specify).....

Please describe the reasons for this referral:

What are the parental concerns?

Birth history where relevant:

Please outline all concerns in the following areas:

	Please include relevant test results / observations to support the referral
Physical health	
Eating /Drinking /Swallowing	
Growth (Weight History)	
Enteral Feeding Regimen	
Intellectual Learning	
Language Skills (understanding and using words)	
Social communication/interaction	

Gross Motor Skills	
Fine Motor Skills	
Self Help	
Vision	
Hearing	
Behaviour	
Sensory processing, e.g. sensitive to touch	
Play	
Speech sounds (pronunciation)	
Fluency (stammering)	

Does the parent / carer have any additional needs or disabilities Yes No

Please give details.....

CONSENT

Please note this referral will only be accepted if both sections 1 and 2 are filled in

- Does the parent/carer consent to this referral? Yes No
- This referral may be discussed in a multi-agency meeting in order to determine the best service/s for the child. Please confirm that the parent/carer has given their informed consent for the **sharing of information** between the services of Whittington Health and London Borough of Islington and partners. Yes No

Name of referrer **Tel No**

Address **Date**.....

Job title/role **Signed**

If you wish to receive confirmation we have received your referral, please give us your **email address**:

.....

Please send this form to: Islington Additional Needs Children's Services central referrals
2nd Floor, The Northern Health Centre
580 Holloway Road
London N7 6LB
Or via **email:** whh-tr.islchildrensreferrals@nhs.net

Please send a copy to the child's GP and keep a copy for your records.

If you have any further queries, please call us on **020 3316 1877**.