University Hospitals of Leicester and
Leicestershire Partnership NHS Trusts

Leicester, Leicestershire and Rutland

Hospital and Community Services

Care Pathway for Children and Adults with Down's syndrome

Birth to adulthood

This document in paper format is only accurate up to the date it was printed.

Please check the LPT website for the most up to date version.

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Introduction

Context

Feedback from families led Community Children's Services and PCT Commissioners to look at their guidelines for managing children with Down's syndrome within existing resources. Input was sought from parent/ carers and other services closely involved with the care of these children.

Multidisciplinary representatives, from Community Children's Services, University Hospitals Leicester (UHL). Commissioning, City and County Early Years Teaching Services, and parents set up a Pathway group to produce a Clinical Pathway emphasising the need for information and engagement with families.

The Pathway produced 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; eg 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?

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

The challenge facing healthcare services is to make the best use of limited resources. Integrated care pathways (ICP's) provide high quality, evidence based best practice that collects variations between planned and actual care (national library for health – www.library.nhs.uk/Pathways)

A Care Pathway aims to have:

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

Recognising Down's syndrome

Background

This is the commonest autosomal anomaly, present in 1 in 600-700 live births.

In Leicester, Leicestershire and Rutland hospitals there are approximately 12 live births per year.

In the majority of cases (95%) there are 47 chromosomes, the extra chromosome being number 21. In 2.5% there is mosaicism, with a population of normal cells being present, and in the remainder of cases a chromosome translocation involving chromosome 21 is involved.

Clinical Features at Birth

General

- Poor Feeding
- Upward Slant of Eyes
- Brushfield Spots in Iris
- Protruding Tongue
- Flat Occiput
- Short broad hands
- Single transverse palmar crease
- Low muscle tone

Facial /Eye

- Prominent epicanthic folds
- Flat nasal bridge
- Short neck
- Congenital cataract
- glaucoma

Limbs

- Short incurved little fingers
- Sandal gap between first and second toes
- Dislocation of knee

Abdomen

- Hirschprungs Disease
- Intrahepatic biliary hypoplasia
- Duodenal atresia / stenosis

Heart

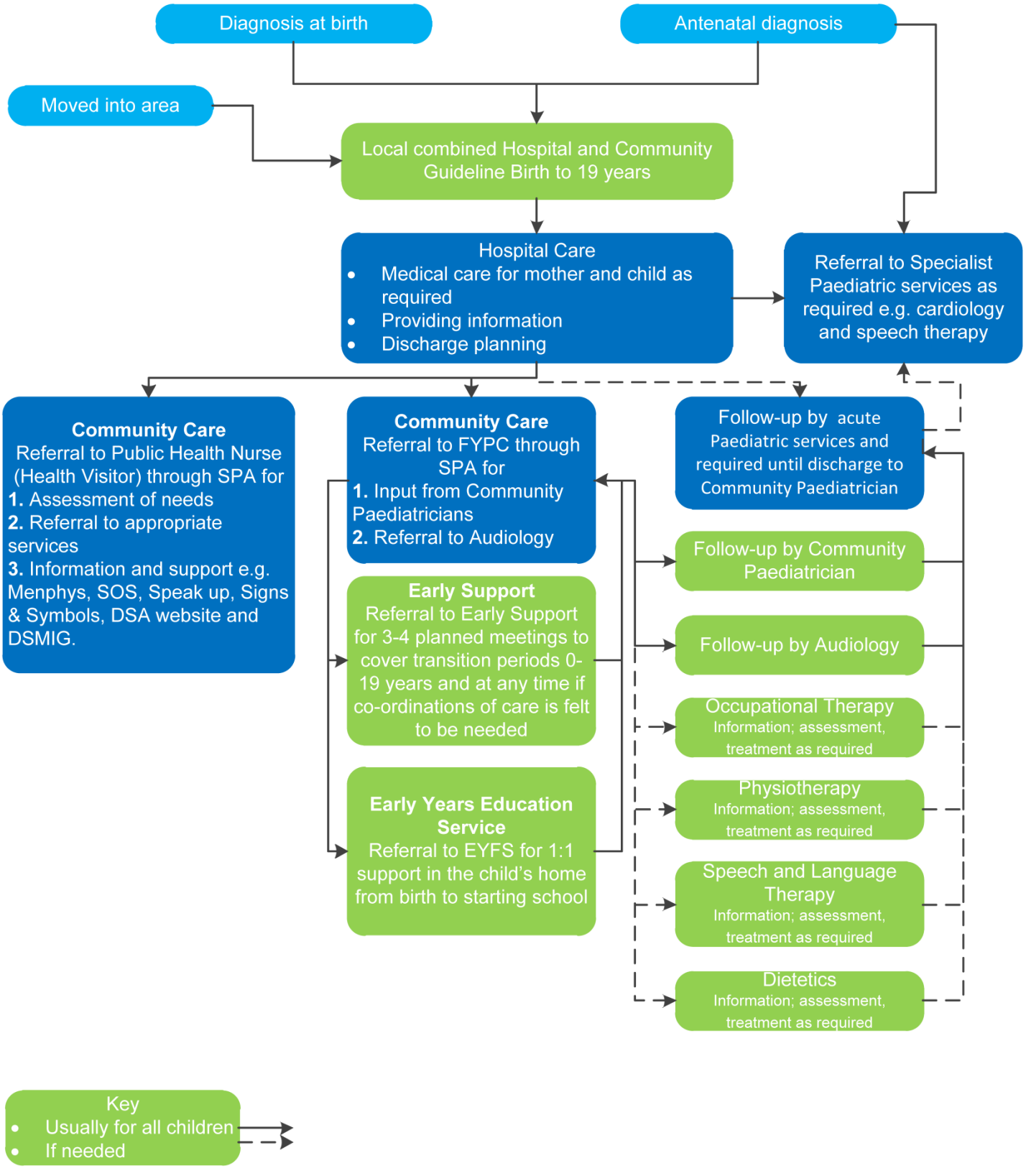
Congenital heart disease occurs in about 40%

- atrioventricular canal
- atrial and ventricular septal defects

Other associated Rarer Problems

- Congenital leukaemia (most commonly AML and acute megakaryoblastic leukaemia)
- Mild pancytopenia
- Neutropenia
- Transient abnormal myelopoiesis
- Polycythaemia

Summary Flow Chart



Hospital Care

Antenatal Care

Hospital Care For Women Booked who plan to give birth under the care of the University Hospitals of Leicester NHS Trust

Screening

Screening for Down's syndrome is an optional test that women and their partners can choose to have as part of their antenatal care in England. This is offered as part of the Trisomy screening tests and for which the couple can also choose to have screening for Edward's and Pataus' syndrome.

The National Screening Committee recommends the use of first trimester combined screening for Down's syndrome, as this test has a detection rate of approximately 85% with a false positive rate of 2-3%. This test can only be performed between 11+2 – 14+1 week's gestation and so for women who book late in pregnancy or for whom the Nuchal translucency could not be measured, maternal serum screening in the second trimester should be offered. This can be performed between 14+2 and 20+0 weeks of pregnancy.

In Leicestershire, all women who book for their maternity care with UHL within the required timeframe will be offered the first trimester combined screening test for Down's syndrome by the Midwife at the initial booking consultation. All other women are offered the second trimester maternal serum test.

UHL also offers all pregnant women a scan at 18-20+6 weeks to look for Fetal anomalies. If an anomaly is suspected by the Sonographer performing the scan, the woman and her partner are referred to a Specialist Fetal Medicine Consultant for a further scan and discussion. If the abnormality identified is associated with features such as Down's syndrome, prenatal diagnosis will be offered.

Women and their partners are directed towards the nationally approved "Tests for you and your baby" electronic information to support the discussions with the Midwife. This information can also be printed if required, with access to this information in different languages and easy read versions. Women are encouraged to read this information prior to choosing to have these screening tests.

High chance results from antenatal screening.

Women and their partners are invited into the chosen Consultant Unit of Birth if they have a high chance result from Antenatal Down's syndrome screening, a low chance result that they are worried about or if they would prefer prenatal diagnosis to screening. At this consultation the Antenatal core Midwives will discuss in more detail the couple's options in relation to prenatal diagnosis. The option of non-invasive prenatal testing (NIPT) or prenatal diagnosis are discussed with the parents if they want more information about whether the baby is diagnosed with Down's syndrome. It is made very clear to couples that it is their choice whether to proceed to further testing, not an expectation.
If the couple choose to have prenatal diagnosis following screening or they have a Fetal anomaly identified on ultrasound scan, an appointment is made to see a Specialist Fetal Medicine Consultant. At this appointment the results of screening/ultrasound are discussed and a further assessment is made. Prenatal diagnosis is then performed by the Fetal Medicine Specialist if the couple request this test.

Couples who choose to have prenatal diagnosis are offered the choice of how they receive their results but this is mainly by telephone.

Babies Diagnosed with Down's Syndrome prenatally
Where a baby is found to be diagnosed with Down's syndrome and the parents had opted to receive the result by phone, the Midwife who informs the family of that result will also have an appointment available for the woman and her partner to attend the Unit within 24 hours to discuss that result in person in more detail.

The couple will be seen by a Fetal Medicine Specialist Consultant and midwife from the Fetal Medicine team. This appointment is aimed to support the woman and her partner at a time when they have received unexpected news and may want to consider options available to them such as continuation of the pregnancy or the option of termination of pregnancy. The couple can be signposted to other agencies if they wish, such as the Down's syndrome association and specialist Paediatric services.

For couples who choose to continue the pregnancy, further investigations will be offered by the fetal Medicine Specialist responsible for their care such as detailed cardiac scans and fetal growth scans later in the pregnancy. In addition, referral to other support services prior to birth is recommended such as Infant feeding Co-ordinators, Public health nursing (health visitor) and local Down's Syndrome support groups at the discretion of the couple.

During the antenatal period the fetal Medicine Obstetric and Midwifery team ensure that the couple are aware that they can contact the antenatal department, Monday – Friday for any queries or support required and assist with communication between the couple and the wider multi-disciplinary / agency team.

In agreement with the family, the family GP would also be notified of the result and referrals.

Managing the Care of Mother and Baby

1. **Establishing And Giving The Diagnosis**
   - Some cases will have been identified prenatally from karyotyping by amniocentesis or chorionic villus sampling (CVS)
   - Genetics do not need to be involved to make the diagnosis except to confirm the karyotype
   - The midwives should call a Paediatric Registrar to see the baby if Down's syndrome is suspected. Provided the clinician is confident, the diagnosis should be disclosed to the parents early on
   - **A Registrar or Consultant should break the news**
   - Confirmation, by means of chromosome analysis should be available within a week
   - Karyotype should be sent to Clinical Genetics in a lithium heparin tube. The cytogenetics lab should be contacted and provisional results are usually available by 48 hours
   - If the test is due just prior to or during a weekend, it is preferable to take a blood sample from the baby on the Monday (unless it is likely to be transfused in which case it should be done before).
2. **The baby should be managed on the postnatal ward, close to his/her mother**

3. Indications for those babies that require admission to Neonatal Unit

- Vomiting – suspect gastrointestinal pathology
- Investigations for delay in passing meconium
- Polycythaemia needing treatment
- Cardiac failure
- Cyanosis
- Anaemia/skin lesions – suspect haematological abnormalities
- Feeding issues
- Any other symptoms and signs that would lead to admission in other babies.

4. Feeding

- The baby must not be discharged until feeding is established and/or the parents have been taught to manage the feeding issues e.g. Nasogastric tube feeding

- Close attention must be paid to feeding; there must be careful documentation of feeds and a daily review

- Information (leaflets available from Early Support*) should be given to the parents/carers on the post-natal ward from birth

- A feeding assessment by the midwife should be carried out for all babies diagnosed with Down's syndrome prior to discharge

- The Infant Feeding co-ordinator to be involved initially if problems occur

- Speech and Language Therapy referral should be made for any baby with suckling or swallowing problems. Speech and Language Therapists with a specialism in eating and drinking are available and able to visit wards at the acute hospitals. Referrals to this team are made via the Children's Speech and Language Therapy Secretaries.

5. Cardiovascular

- If the cardiovascular examination is normal, an echocardiogram needs to be preferably undertaken within the first week of life. Refer to paediatric cardiology department at the Leicester Royal Infirmary by calling the on-call paediatric cardiology specialist registrar and follow this up by sending an email of the referral form/ electronic referral form. There are new patient clinics for cardiac review most weeks and also ward review slots can be utilised.

- **An ECG is a useful adjunct and should be performed on all neonates with Downs Syndrome.** If congenital heart disease is suspected clinically, contact the cardiologists for a more urgent assessment.

- Those with abnormal clinical signs or ECG abnormality (in particular a superior QRS axis) are potentially at a higher risk for important congenital heart disease.

- Those with no abnormal clinical signs or ECG abnormality on initial examination may nevertheless have cardiac disease. There is a possibility of undiagnosed abnormality becoming symptomatic. The parents should be made aware of the symptoms of this and given an action plan if they are discharged prior to echo taking place.

- For those neonates with prenatally diagnosed Down's syndrome who have had normal detailed prenatal cardiac screening, follow the individual prenatal instructions for cardiac follow-up. In general, this is likely to be a recommendation for referral for a postnatal echocardiogram around 6 weeks to 3 months of age to ensure the atrial septum and arterial duct have closed postnatally and to exclude other more minor forms of congenital cardiac anomaly
- For those neonates in whom an associated cardiac anomaly has been detected, follow-the prenatal management plan, but remember that clinical assessment of any patient can supersede a prenatal plan and contact the on-call paediatric cardiology SpR or consultant as a matter of urgency if there are clinical concerns about congenital heart disease.

- Babies diagnosed later in the neonatal period need paediatric cardiology assessment in the same way, ideally before 6 weeks of age.

6. Screening

- The NIPE check should be completed within 72 hours of birth if the baby is well.
- Hearing screening and the Newborn blood spot screening are particularly important for these babies and must not be missed.
- If Down's syndrome is suspected or confirmed, the NIPE should be completed by a neonatologist.

7. Information to Parents/Carers

- Information for the parents and carers is very important and can be given in discussions with them, whilst on the ward.

- Discussion with the family should include the following but needs to be sensitive to the needs of the family at the time:
  - Explanation of the condition
  - Genetics of the condition
  - Local resources – eg. red book insert
  - Contact details of Down's Syndrome Association
  - Alerted to medical conditions associated with Down's syndrome

- There are some excellent publications, by the Down's Syndrome Association and the Down's Syndrome Research Foundation in the UK.:
  - www.dsmig.org.uk
  - Bright Beginnings – Newborn Parent guide (Down's Syndrome Research Foundation in UK)- https://www.dsrf-uk.org/parents-carers/new-parents/
  - Pregnancy and Baby (Down's Syndrome Association)- https://www.downs-syndrome.org.uk/about-downs-syndrome/pregnancy-and-baby/
  - Looking forward to your baby (Downs Syndrome Association)- https://www.downs-syndrome.org.uk/wp-content/uploads/2020/08/Looking-Forward-to-Your-Baby.pdf
  - Health and wellbeing for people with Down's syndrome (Down's Syndrome Association)-https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/
- Copies should be kept on the neonatal unit so that they can be given to parents when required.

- There are copies available in different languages.

- At the LRI this literature should be kept by the baby care assistants and should also be present in the quiet room.

- At the LGH, it is kept in the sisters' office. It is also possible to access it from the internet.

8. Referrals

A SPA referral form should be completed to refer the baby to family, young person and children's services. (See Appendix 3)

Following SPA, children will be offered any Community Health Services for difficulties apparent in the referral at that time.

In addition, the Public health nurse (Health Visitor) will make contact with the family following the birth at 10-14 days old and will offer

- a comprehensive assessment of need
- discussion and information about local services available to them
- Referral to community health professionals as identified at that point.
- Ongoing review and support at key transition stages if required.

If the 6 week specialist paediatric review (see Paediatric Medical Guideline- page 14) is to be carried out by the Community Paediatrician (ie not by the hospital consultant) this should be made clear on the SPA referral form.

Discharge Planning

The timing of discharge will vary. Ideally the baby should not be discharged sooner than 48hours after birth (Appendix 5).

Checklist – see Appendix 5 – MUST BE COMPLETED for all babies affected with Down's Syndrome.

1. The baby must be feeding satisfactorily.

2. Check weight before discharge- this must be within the past 48 hours.

3. The GP and Public health nurse **must** be informed of the diagnosis of Down's syndrome on the discharge letter.

4. **Echocardiography should either have been done, or a plan put in place for it to be done ideally within a week, in consultation with the paediatric cardiologists.**

   There is a possibility of undiagnosed abnormality becoming symptomatic. The parents should be made aware of the symptoms of this and given an action plan if they are discharged prior to echo taking place.

5. **Down's specific inserts for the 'Red Book'.** There is a 20 page insert for the Red Book which contains additional information for parents and professionals. The areas covered include general information, expected developmental progress, possible health problems, suggested schedule of health checks and Down's specific growth charts.

   This should be inserted before discharge. Birth weight and head circumference plotted.

The *neonatal assistants should have these sheets.*

6. In rare cases, the chromosome results may come back after discharge. In this circumstance, it is important to make a plan with the parents for how the information will be given to them. This needs to be arranged with the consultant. Best practice would usually be a face to face consultation. However, the parents may wish for alternative arrangement.

7. Referrals: Ensure all necessary referrals have been made before discharge. This should always include a referral to Community Child Health Services (using the SPA referral form – Appendix 3).
   Please make sure that the baby's parents/carers are aware of all referrals made.

8. After discharge, the family should contact their community midwife (until is care handed over to the Public health nurse) or GP if they have concerns. If the baby is acutely unwell urgent medical attention should be sought.

Follow-up

Provided there are no outstanding medical issues, follow-up should be arranged with the nominated consultant. This should happen at 4-6 weeks of age.

As above, the local guideline for medical management suggests specialist review at 4-6 weeks of age. If this review is to be carried out by the Community Paediatrician (ie not by the hospital consultant) this should be made clear on the SPA referral form.

Community Care – Management of the Child in the Community

Referral

The child can be referred into the service at any point. The different disciplines have referral criteria which are available on the Leicestershire Partnership Trust website. http://www.leicspart.nhs.uk/

Referrers need to use the SPA (Single Point of Access) referral form. This is also available on the LPT website. If the 6 week follow up for a baby born outside Leicester, Leicestershire and Rutland but living in the area is identified, the referrer needs to complete the SPA form and also make it clear that the 6 week check has to be completed by the community paediatrician.

http://www.leicspart.nhs.uk/SearchResults.aspx?s=SPA+referral

Referrals are discussed at the SPA meeting on a weekly basis.

The SPA group brings together a multi-disciplinary team of health professionals from within Families, Young people and Children's services.

Referrals are initially checked by the receiving clinician e.g. by a Consultant or Therapist. For cases where there is lack of clear information given in the referral letter and/or where the referral letter indicates that the child may have complex health needs, the clinician will forward the referral letter onto the SPA for discussion.

Following SPA, children will be offered any services for difficulties apparent in the referral at that time.

The Universal offer to all families

Healthy Together is a public health programme provided by Leicestershire Partnership NHS Trust for children and young people and their families aged 0-19 across Leicester City and0-11 years within Leicestershire and Rutland.

Healthy Together includes public health nursing services (previously known as health visiting and school nursing), giving families the care, they need including early help if necessary. The service offers universal contacts to all children as part of the Healthy Child Programme (HCP). This includes additional support and advice to families where there are additional needs to support them achieving their optimum potential. In addition, the Public health nurse (health visitor) will make contact with the family within 4-6 weeks of a SPA, referral if not already known to the service.

This will include

- a comprehensive assessment of need
- discussion and information about local services available to them
- Referral to community health professionals as identified at that point.
- Support and review at key transition stages if required
- The Down's syndrome pack if the family/carer prefer to have one

The Public health nurse (health visitor) will also make information on local services available to families / carers when appropriate – not all families will want this early on. This could include:

- Pathway and flow chart
- Menphys / Early Support Information for parents/families
- National Down's Syndrome association
- Local Down's Syndrome group
- Local health services information on other professional services
- Early Years Education Services (and referral when appropriate)
- Benefits advice / signposting
- Other local groups / services
- Speak Up
- Signs and Symbols course
- STEPS
- Local additional needs play / support groups (eg Birstall, Sunflowers)

Discharge

Children will be discharged from individual services when appropriate with agreement with parents/ carers.
Parents/ carers need to be aware that all services have a policy to discharge following 1 or 2 non-attendances.

Managing On-Going Health & Development Needs Hospital and Community Children's services

Paediatric Medical Guideline

The following guideline is based on information from the DSMIG (Down's Syndrome Medical Interest Group). This group of clinicians, who have a special interest in Down's syndrome, have produced, and regularly review, surveillance guidelines on the basis of available evidence.

This guideline is currently designed to be used by paediatric medical staff, in Hospital or Community settings, to assist them in delivering good quality care to children with Down's syndrome. ie the medical assessments referred to in this section are intended to be carried out by paediatricians.
Primary care services are welcome to refer to it for information.

This guide should be used in conjunction with the locally produced checklist (please see appendix 4) and referring to DSMIG website for up to date information.

Most children with Down's syndrome will be born in hospital and diagnosis is likely to be made then, although can sometimes occur later.

Some children will be born out of area and will need to be referred into local services by their Public health nurse (health visitor) or GP.

Relevant web sites:

- https://www.dsmig.org.uk/
- Home - Downs Syndrome Association (downs-syndrome.org.uk)

Notes on Local services

Audiology

In Leicester the audiology service offers hearing assessment every 6 months pre-school and yearly thereafter. The children cannot access the service automatically, so need direct referral to audiology as soon as possible so that they can enter the screening programme.

Orthoptics

The orthoptic clinic will offer an assessment at 2 years and 4 years for screening if the children are referred to the orthoptic clinic at these times and at any time in-between if a problem is thought to exist.

Endocrinology

Facilities for finger-prick testing for TFT's are not routinely available at present and therefore TFT monitoring is to be offered by venepuncture. The frequency of performing this test depends on the blood results. Some children may have a shared care with the paediatric endocrinologists if they are on Thyroxine supplements. If the child has been discharged to the community paediatricians, TFT's should be done annually or as advised by the endocrine team on discharge. Any abnormal TFT's or decisions to change to dose of Thyroxine should be made after discussion with the endocrine team. If the child is under the care of the endocrine team, monitoring of TFT's is by them.

https://www.dsmig.org.uk/wp-content/uploads/2020/04/FINAL_Thyroid-Disorder-in-Down-Syndrome-Guideline-with-all-logos-v7.1_230420.pdf

The First Year

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

- 6 weeks
- 3 months
- 6 months

6 Week Review

History to include:

- Developmental assessment
- Medical problems particularly those known to be associated with Down's syndrome – see Appendix 1

Examination to include:

- Cardiovascular exam
  Rarely, echocardiography, particularly in the first few days after birth, may fail to diagnose AVSD and other major shunt lesions. Hence there should be a low threshold for repeating this investigation if symptoms or signs of cardiac disease are detected at any age even in the presence of 'normal' early echocardiogram. (*DSMIG guidelines: Personal communications. Archer, Dennis, Ward*)
- Check for cataracts
- Plot growth & OFC on Down's syndrome Growth Chart – if low consider other pathology if there are no heart concerns

Tests:

- Check blood test results from newborn period ie chromosomes and TSH on Guthrie card
- Check that Neonatal Hearing test has taken place and the results
- Check cardiology assessment is completed

Referrals:

- Specialist Community Child Health Services
- Paediatric Cardiology if not already done
- Refer to audiology

Discussion with Carers to include the following:

- Explanation of the condition
- Genetics of the condition and associated medical conditions
- Make sure red book insert has been given to parents
- Local resources and contact details of Down's Syndrome Association

Follow-up: Arrange to see at 3 months

3 and 6 Month Reviews

History to include:

- Any concerns
- Feeding
- Hearing and Vision
- Development
- Ongoing medical problems e.g. cardiac/bowel, infections
- Professionals involved and local support
- Local resources, Down's Syndrome Association etc

Examination to include:

- General examination
- Growth (plot on Down's syndrome growth chart) Children with Down's syndrome are at greater risk of conditions that can result in poor growth e.g.congenital heart disease ; sleep related upper airway obstruction; coeliac disease; nutritional inadequacy due to feeding problems; and thyroid hormone deficiency.
- Heart
- Eyes (visual behavior , squint, nystagmus, cataract)
- Ears (check hearing test is arranged)
- Developmental assessment

Investigations:

- As clinically indicated
- Ensure vaccination is up to date
- Check T4, TSH and TPO at 4-6 months

Referrals:

- Hearing (at 8-10 months) a full audiological assessment including thresholds, impedance and otoscopy
- Genetics if not already done
- Local Education Authority Early Years Teaching Service via section 23
- Portage if County
- Endocrine team if TFT's are abnormal
- Speech and language communication team at 9 months
- Referral to appropriate therapy if indicated i.e. the child has a significant delay or difficulty over and above that which would be expected for a child with Down's syndrome (contact the relevant therapy dept. for further details if required).

Follow-up: Arrange to see at 6 months, or 1 year as relevant unless indicated otherwise

Preschool Years (Ages 1 to 5 years)

History to include:

- Parental concerns
- Development/education
- Growth
- General health including symptoms of upper airway obstruction/other respiratory problems/GI tract problems, infections
- ENT
- Spine including any neurological symptoms
- Hearing and Vision
- Sleep difficulties / symptoms of obstructive sleep apnoea

Examination to include:

- General examination including skin conditions and cardiovascular
- Ears and Eyes
- Growth (plot on Down's syndrome growth chart) Children with Down's syndrome are at greater risk of conditions that can result in poor growth e.g.congenital heart disease; sleep related upper airway obstruction; coeliac disease; nutritional inadequacy due to feeding problems; and thyroid hormone deficiency.
- Rapid weight gain should prompt check of Thyroid function

- Developmental assessment
- Neurological examination
- Lower limb alignment and footposition when weightbearing e.g standing, walking. If feet are rolling inwards (valgus ankle) refer to orthotic department.

Investigations to include:

- Thyroid function
  - Venepuncture annually including T4, TSH, thyroid antibodies
  - Please follow DSMIG guidance in case of abnormal results. The urgency of repeat bloods varies on levels of TSH, T4 and the age of the child.
  - Have a low threshold for testing thyroid function at other times if clinically indicated.
  - Testing should be continued throughout lifetime.
  - If child is already under the endocrinology team on Thyroxine supplements, please leave monitoring of TFT's with the endocrine team.
  - If child has been discharged from the endocrine team with Thyroxine supplements, perform annual TFT and liaise with the endocrine team if results are abnormal to identify any change in dose.
- **Recurrent infections**
  - Please refer to 'Immunology guidance for children with Down's syndrome' for reference and investigations- Appendix 7

Referrals:

- Audiology: refer at 15-18 months and yearly follow up if not under them.
- Opthalmology: refer for full ophthalmology assessment at 2 and 4 years unless otherwise indicated
- Specialist gastroenterology/respiratory/ immunology services if indicated
- Orthotic department for suitable ankle/foot support. (as above)
- If lower limb alignment is excessively abnormal e.g severe valgus knees or feet refer to orthopaedic consultants for monitoring.
- Refer for sleep studies at 3-4 years or earlier if symptoms of OSA including sleep study- Appendix 1

Follow-up Annually unless otherwise clinically indicated

School age (4 years Onwards)

History to include:

- Parental concerns
- Development/education
- General health including respiratory and GI tract symptoms
- ENT
- Spine including any neurological symptoms
- Hearing and Vision
- Sleep difficulties / symptoms of obstructive sleep apnoea

Examination to include:

- Growth - plot on Down's syndrome growth chart and plot on BMI chart if weight >75th Centile
  Children with Down's syndrome are at greater risk of conditions that can result in poor growth e.g. Congenital heart disease; sleep related upper airway obstruction; coeliac disease; nutritional inadequacy due to feeding problems; and thyroid hormone deficiency. Rapid weight gain should prompt check of Thyroid function

- Ears
- Eyes
- Cardiovascular and neurological examination

Investigations to include:
- Hearing – referral to audiology every 2 years unless indicated sooner
- Vision – should be checked every 2 years either at local optician or ophthalmology department as required unless indicated sooner
- Thyroid function –should be checked annually by venipuncture, unless indicated sooner. Perform annual TFT's if the child is on Thyroxine supplements.
- Check TSH, T4 and thyroid antibodies
- Follow DSMIG guidance and liaise with paediatric endocrinology in case of abnormal results.
- Around 10% of the school age population have uncompensated hypothyroidism. The prevalence increases with age. Clinicians should have a low threshold for testing thyroid function if there is any clinical suspicion at times between biochemical testing.
- As in the general population, key clinical pointers are lethargy and/or changes in affect (eg depression), cognition, growth, or weight.
  - If concerned about recurrent infections, please refer to 'Immunology guidance for children with Down's syndrome' for advice and investigations- Appendix 7
  - Ensure children have their flu vaccines annually.

Follow-up: Annually unless indicated otherwise

School Leaver (Usually Prior to 19th Birthday)

Discussion with Carers to include:
- Health to date
- Future health
- Further education, employment, daycare

Examination to include:
- General
- Growth
- Cardiovascular and Neurological examination

Tests to include:
- Hearing
- Vision
- Thyroid function
- Flu vaccine annually

Referrals:
- Cardiology- clinical review may be indicated for cardiac symptoms or new murmurs. However, routine referral to congenital cardiology is not indicated.
- Ongoing hearing surveillance is essential
- Adult endocrine team if already under Paediatric endocrine services
- Adult learning disabilities team (See care pathway for adults with Down's syndrome- page 26)
- Social services disabilities team
- GP for ongoing surveillance

Introduction to Children's Therapy

- A wide range of services are available, if required by the child. Not all children with Down's syndrome will require intervention by physiotherapy or occupational therapy teams.
- There are referral criteria which must be met for the child to be seen by each of these services.
- It is not always necessary for the child to be seen by all or any of these different therapies.
- Following referral and assessment, appropriate treatment will be offered to meet the child's individual needs.
- The approach to a child's treatment 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, they can be (re-)referred to therapy services.

Physiotherapy and Occupational Therapy

Referral

- This would come from another health professional and will be considered at the SPA meeting (see above).
- If the referral criteria are met, the child will be offered an assessment appointment. (Children with Down's syndrome will be accepted into the service for provision of toileting equipment etc as per usual criteria where there is a functional need.)
- For some services, such as the provision of specialist footwear or ankle splints, the child can be referred directly to Orthotics without an initial PT/OT appointment. (Appendix 10 and 11).

Assessment

- The child's individual needs will be assessed and a plan for any treatment needed be devised.

Treatment

- This will be specific to the child's needs.
- It may be delivered in a variety of ways, such as advice, individual sessions, group sessions, advice to carers.
- It may be delivered in a range of settings, such as clinic, pre-school placement, school placement, school.

Discharge

- Once the child has achieved the targets set by the therapist and agreed with by the family/carers, they will be discharged from the service.
- If the child's needs change in the future we are happy for them to be referred.

Speech and Language Therapy

Speech and Language Therapy for Communication for Children with Down's syndrome

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

Your child can be referred for speech and language therapy. The Speech and Language Therapy Service has an open referral system. This means that any professional can refer your child (with your permission), or you can do this yourself. Please look at the Leicestershire Partnership NHS Trust website for the referral form and for information on what to expect from speech and language therapy.

Children with Down's syndrome have complex needs. They are not simply 'developmentally delayed' but have a specific communication profile with characteristic strengths and needs. Not all children with Down's syndrome will require regular input from a speech and language therapist, but the majority are likely to need specific strategies to support communication. The type and level of support will depend on the child's individual needs but should start early. Ideally, children should have been assessed by a speech and language therapist between 9 months and 12 months of age. The paediatrician, public health nurse (Health Visitor), GP or parents can make a referral to the Speech and Language Therapy Service. The Service usually considers referrals for support with communication from 6 months of age for children with complex needs. Referrals for children with feeding and swallowing difficulties can be referred from birth, if difficulties are identified.

There are some very helpful resources for parents on the DSA website:

Speech, language and communication - Downs Syndrome Association (downs-syndrome.org.uk)

Communications Series - Downs Syndrome Association (downs-syndrome.org.uk)

Following referral, a speech and language therapist will meet with you to talk about your child's speech, language and communication needs. All children are different, and can communicate in different ways, so the support offered will be tailored to the needs of your child.

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

- Assessing your child's communication skills and needs
- Working closely with Portage and Early Years Teachers to agree evidence-based communication aims and strategies for your child
- Working closely with nursery and school staff to help them support your child's communication
- Offering individualised training to nursery and school staff, as appropriate
- Offering evidence-based individual or small group therapy to achieve specific speech, language, and communication goals in episodes of care
- Offering Signs and Symbols online workshops for parent and carers (Appendix 12)

When your child's speech, language and communication needs are being met, by you as their parents and / or by their school, there will be times when they do not need the specialist support of a speech and language therapist. Your child's speech and language therapist would discuss this with you and your child's teachers.

If you have any questions, or if you would like to speak to a speech and language therapist, please ring the Children's Speech and Language Therapy Service on 0116 295 5256.

Further information

https://www.leicspart.nhs.uk/base/childrens-speech-and-language-therapy-service/

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

https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/speech-language-and-communication/

Leicestershire Down Syndrome Group –

https://the-leicestershire-downs-syndrome-group.webnode.co.uk

Speak Up – a communication group for babies and pre-school children run by parents. Contact via email – leicesterdowns@gmail.com

Kumin, L. (2012) 3rd Edition, Early Communication Skills for Children with Down Syndrome – A guide for parents and professionals.

Kumin, L. (2008) Helping Children with Down Syndrome Communicate Better – Speech and Language Skills for Ages 6-14.

Ask-the-Experts-Downs-syndrome-bulletin-august-2020.pdf (rcslt.org)

Down's syndrome and autism

A small number of children with Down's syndrome may also have autism. Your child's speech and language therapist will work with you and your child's paediatrician in the assessment and diagnosis process. For more information about Down's syndrome and autism please look at

https://downs-syndrome.co.uk

or follow this link:

https://www.downs-syndrome.org.uk/wp-content/uploads/2021/04/Diagnosing-ASD-in-a-child-who-has-Downs-syndrome.pdf

Speech and Language Therapy Pathway for Eating, Drinking and Swallowing Difficulties in Children with Down's syndrome

Feeding a child with Down's syndrome can have its challenges. This is due to a number of complicating factors which may affect both feeding development and feeding safety. These may include:

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

If your child is having difficulties with feeding/eating and drinking (sometimes called dysphagia) they may need some help from a Speech and Language Therapist.

Our Service

The Speech and Language Therapy Service has an open referral system. This means that any professional can refer your child (with your permission) or you can do this yourself. Please look at the Leicestershire Partnership NHS Trust website below for the referral form and for information on what to expect from speech and language therapy.

The Speech and Language Therapist will work as part of your child's multi-disciplinary team by assessing the feeding difficulties and identifying the areas that need addressing in order to keep them safe and healthy.

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

- Ongoing assessment of your child's feeding/eating and drinking skills
- Working closely with other health professionals, such as your Public Health Nurse (Health Visitor) or Dietician, to provide you with strategies to help with feeding /mealtimes and/or a programme of specific activities
- Working closely with nursery and school staff to meet eating and drinking needs
- Offering training to nursery and school staff, as appropriate

When your child's eating and drinking needs are being met, by you as their parents and / or by their school, they may no longer need the additional support of a speech and language therapist. Your child's speech and language therapist would discuss this with you and your child's school.

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 0116 295 5256.

Further information

- http://www.rcslt.org/speech_and_language_therapy/what_is_an_slt
- rcslt-infant-dysphagia-factsheet.pdf
- http://www.downs-syndrome.org.uk/for-families-and-carers/growing-up/feeding/

Dietetics

Referral

- This can be made by another health professional via PRISM referral (see referral form Appendix-6)

Assessment

- The child's individual needs will be assessed and a plan for any treatment needed be devised.

Treatment

- This will be specific to the child's needs.
- The appropriateness of the treatment will be regularly reviewed and, if needed, changed to reflect the needs of the child at that time.
- It may be delivered in a variety of ways, such as advice, individual sessions or advice to carers.
- It may be delivered in a range of settings, such as clinic and school placements.

Discharge

- Once the child has achieved the targets set by the dietitian and agreed with by the family/carers, they will be discharged from the service.
- If the child's needs change in the future we are happy for them to be re-referred.

Early Years Education Support

Early Years Support Team- Leicester City

Referral
This can be made by any professionals or parents via direct referral.

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. At first, support is likely to consist of home visits and ongoing advice to parents regarding their child's development in the areas of language, motor and play skills and personal, social and emotional development. The child's needs will be monitored through the Early Years Child Passport (information and targets reviewed every 4 months) or for some children through the Education, Health and Care Plan process
Information will be provided regarding the 'Family Fun' stay and play sessions which take place weekly during term time at New Parks House Pindar Road Leicester.

As the child gets older support and advice is available to enable smooth transition to settings and school. We will continue to provide support and advice to settings and school and also offer training for practitioners.

Support will be provided by the Early Years Support Team during the Foundation Stage. Children will continue to receive support from the Special Educational Needs and Disability Support Services (SENDSS) during their school years.

The Early Years SEND Inclusion Service Leicestershire

The Early Years SEND Inclusion Team is part of the Early Years Inclusion and Childcare Service. Within our team, there is the Early Years SEND team, Early Years Autism Outreach and Portage- **https://www.portage.org.uk/leicestershire-portage-service**

The Advisors and the Practitioners in the Team support babies and children with complex and significant special educational and additional needs and their families.

Referrals for all of the team are made via the Early Years SEND Panel (monthly meetings). At this meeting, every child referred is discussed and it is decided which Education service (or services) are best placed to meet the child's needs.

Early intervention is crucial to empower parents and carers to help their children to reach their full potential.

Our teams support can be at home, at the child's early years setting or a combination of both.

Educational Psychology

The Leicestershire County Educational Psychology Service
Children with Down syndrome will be allocated to an Educational Psychologist at the point of referral to the Early Years' Panel. This will usually mean that a child with Down syndrome will

have involvement from an Educational Psychologist from an early age, usually under a year and often earlier.
The EP will visit the child and their family, usually at home within a short time to introduce themselves, outline their role and to listen to what parents are saying and ask questions in order to make use of the detailed knowledge parents have about their child and offer emotional support where appropriate.

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

- Visiting the child and parents at home
- Visiting the child at home and at Early Years' setting
- Liaising closely with other professionals involved(including those who work very regularly with the family(eg EYSENIS and Portage))
- Attending meetings (eg Early Support meetings)where appropriate

They will also be involved in:

- Giving advice and support to adults working closely with the child, including social and emotional aspects of learning, child development, play.
- Discussing options for early years provision, including specialist and local provision
- Discussing plans for school entry including initiating and explaining Statutory Assessment where appropriate.

The Psychology service works alongside other services to produce and run training for EY settings and schools on supporting children with Down syndrome in settings/schools.

CAMHS learning disability services

CAMHS LDT provide assessment and treatment for children and young people with a moderate to profound Intellectual Developmental Disability (IDD) as defined in ICD 11 for mental health problems and associated behavioural difficulties and/or for complex high risk behaviours understood within their Intellectual Developmental Disability and co-morbid conditions up to the maximum age of 18 years where assessment and input has already been undertaken but sustained change not maintained. (Referrals for 17 years 9 months would be redirected to adult LD health services unless urgent and/or high risk).

In line with multiagency care pathways we also undertake Neurodevelopmental assessments for secondary school aged children, in regards to ASD and ADHD for diagnosis. Treatment may be initiated if indicated appropriate in regard to symptoms of ADHD.

Assessment of sleep problems is undertaken when identified as behavioural in nature or disruption caused through medication prescribed via CAMHS LDT. It is expected however, that initial input has been sought via the school nurse (health visitor) / paediatric services.

Behavioural input follows a pathway the of Positive Behaviour Support Framework with the undertaking of a child centred Core support assessment and management plan, understanding behaviours and functional behavioural assessments if required. This work is undertaken via parent / carer workshops and 1;1 with parents unable to attend a workshop.

Input for mental health problems can be via pharmacological and / or psychological treatment options as well as behavioural input.

Early Support

Introduction
Early Support is a national programme which aims to improve the way that services for young children with disabilities in England work with families.

In Leicestershire, Leicester and Rutland in partnership with Menphys SOS and Leicester's Children's Centres, Early Support is used to provide family key working and co - ordination for children and young people aged 0-19 that have complex health needs, disabilities and/or special educational needs

Aims
Early Support promotes services for families and children that:

- Work in partnership with parents and carers, so that families are at the heart of discussion and decision-making about their children.
- Integrates service planning and delivery, particularly when families are in contact with many different people and agencies.

Referrals
These can be made by parent-carers or professionals from the statutory or voluntary sector. Once a referral has been received and agreed then the family will be allocated an Early Support Key Worker who can support the family by ensuring that:

- There is a single point of contact for the family and all professionals working with them and their child.
- Someone has time to listen the family's views and the views of the child/young person.
- Parent-carers don't have to keep telling professionals all about their child over and over again.
- Professionals working with the child share information to reduce duplication.
- Parent-carers have all the information they need to support them.
- Where possible appointments and assessments are arranged at convenient times.
- Where needed, Early Support multi agency meetings are arranged to discuss the child / young person's needs at which the child/young person's progress is discussed and a joint family service plan is developed, which includes 'Next Steps' for the child/young person and how these will be delivered and reviewed.

The need for on-going input from Early Support is evaluated at the end of each meeting. When services around the child and family are in place and effectively co-ordinated, there may no longer be a need for further meetings.

For children on the Down's syndrome Care Pathway it is expected that 3-4 planned meetings will take place to cover transition periods, birth to 19 unless needs dictate otherwise.

Useful links
www.menphys.org.uk

Care pathway for adults with Down's Syndrome

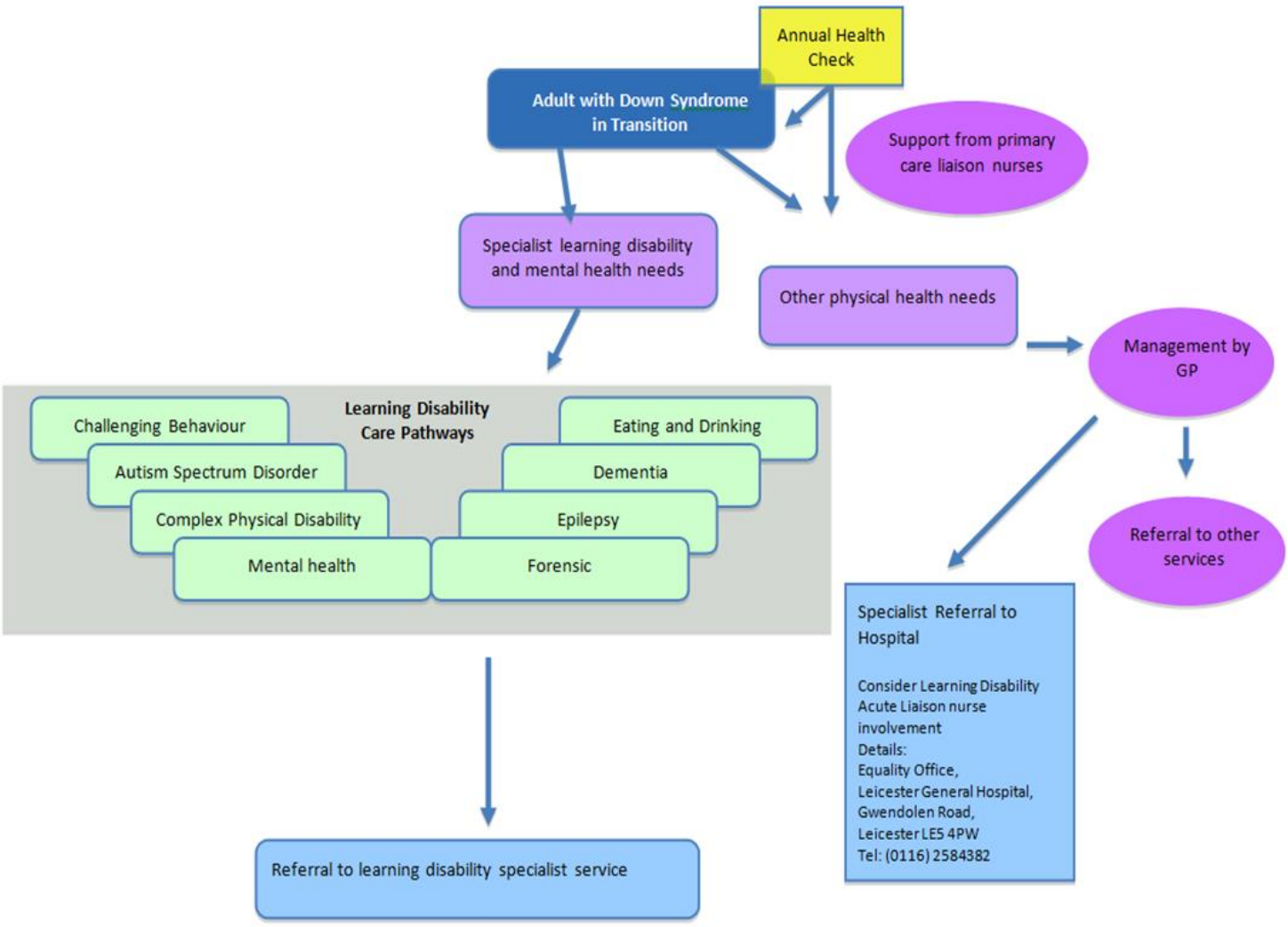
Introduction

The development of the Down Syndrome Care Pathway is an integrated care pathway that outlines or maps the anticipated care a person with Down's syndrome may receive in adulthood from a multi-disciplinary and/or multi agency care team. It incorporates both mental health and physical health needs and is designed to help the person move progressively through the clinical experiences to a positive outcome.

It is essential that we can support adults with Down syndrome to lead healthy and fulfilled lives and to achieve the level of independence right for them. One of the ways we can do this is by access to good healthcare and social care, including a range of different specialists.

People with Down syndrome on the whole do not have medical problems different from those in the general population. However, some medical conditions are more likely. Most of these are treatable disorders which, if undiagnosed, impose an additional but preventable burden.

Summary Flow Chart



Transition of Care

Transition for community paediatric and specialist paediatric care will occur from the age of 18 years. The transition plans should be explained to patients and carers, and they should have a named professional contact during the transition period. Transfer of care should be to the GP and /or adult specialist services for physical health interventions and to the learning disability services for mental health, behavioural or epilepsy related interventions, if applicable.

Health needs for adults with Downs Syndrome (DS) and Suggested Screening

- **Depression:** Depressive illness is more common in people with DS and mental health problems generally are more common in people with learning disability.
  Mental health assessment may be required if the patient presents with changes in behaviour or mood, or loss of skills. Changes such as sustained periods of low mood, crying spells and not enjoying things.

- **Dementia:** Alzheimer's dementia occurs much more commonly and earlier in people with DS.
  Dementia screen should be done if the patient presents with loss of skills or other changes in behaviour or seizures. Baseline functioning should be established early in people with DS (See 'Ageing with Downs Syndrome'- Page 30).

- **Teeth:** The facial features of individuals with DS contribute to a variety of potential dental problems.
  Six monthly dental review should be completed.

- **Cardiac:** 40 - 60% of people with DS have congenital heart problems and new valve problems may present in adult life.
  Cardiovascular auscultation is part of the annual health check, one echocardiogram in adult life is recommended and antibiotic protocols should be in place for those with pre-existing heart problems. Referral to Cardiologist should be made based on findings

- **Breathing** Obstructive airway disease is a significant problem people with DS.
  Snoring, unusual sleeping positions and fatigability during the day should be evaluated using Polysomnography. Overnight pulse oximetry may be beneficial.

- **Spinal** Up to 70% of people with DS are at risk of problems caused by cervical spine disorders including degenerative disease, cervical spondylosis and atlantoaxial instability.
  Asymptomatic individuals should not be barred from normal sporting activities. Neurological function should be evaluated annually as part of the Annual Health Check.
  If presenting with warning signs (neck pain, abnormal head posture, reduced neck movements, falls, increased fatigue and deterioration in manipulative skills) – clinician should complete general physical and neurological examination and check for cord problems. They should also consider cervical spine X-rays or CT/MRI. A specialist referral should be made if there is an abnormality.

- **Gastrointestinal:** DS increases the risk of gastric reflux and coeliac disease.
  Clinical screening for coeliac disease and gastro oesophageal reflux disease (GORD) should be carried out if people with DS present with symptoms such as pain, weight loss or change of bowel motions.

- **Obesity:** Up to 95% of those with DS are over-weight or obese.
  Weight and BMI should be taken at Annual Health Check.

- **Endocrine** Diabetes Mellitus and Hypothyroidism are common in people with DS. Hypothyroidism presents with symptoms such as fatigue, weight gain or decline in skills.
  Thyroid function tests should be completed annually and blood sugar/HbA1c blood tests if they have risk factors for diabetes.

- **Bones** Osteoporosis affects up to 50% of men and women with DS.
  Screening in women should be started no later than the start menopause or age 50, whichever comes first. Screening should be completed based on risk factors which include anti-epileptic medication, anti-psychotic medication, poor mobility and poor nutritional status.

- **Ears** Sensorineural and conductive hearing impairment is present in over half of people with DS.
  Ear examination should be completed every two years and audiology if indicated.

- **Eyes** Almost half of people with DS have strabismus and other ophthalmological problems include refractive error, nystagmus, congenital cataract and glaucoma.
  Full assessment by Optometrist / optician should be completed every two years.

- **Immunity and Infections** People with Down's syndrome are more likely to develop infections, such as lung infections.
  Clinical assessment for common infections should be carried out if people with DS present with symptoms such as pyrexia or cold-like symptoms. Immune function tests should be considered for those with frequent infections.

Care of Adults with DS

The differential diagnosis of a decline in skills and change of behaviour includes:

- Hypothyroidism
- Sleep apnoea or other sleep problems
- GORD or coeliac disease
- Depression or other mental health problems
- Hearing or visual loss
- Dementia
- Iatrogenic (medication related) causes
- Seizures
- Environmental changes such as routine or life event such as bereavement
- Abuse

Following initial assessment and treatment, further evaluation may include the involvement of specialist learning disability services (see ‘The Adult Learning Disability Service’ section below- Page 32).
Involvement in care and treatment should be optimised through adapted communication, help to understand information such as accessible leaflets and support to make decisions. Strategies to aid consultation include:

- Offering increased consultation time

- Use language that the person understands at a simple level, or use a communication aid, i.e. pictures or symbols
- Carers are usually key resources for support, but it is important to remember that carers may need support as well

People with DS generally do well within supported environments with predictable routine and schedules, and routines learning may lead to improved adaptive skills.

Ethical and Legal Issues
Many people with DS require support and advocacy in making medical and legal decisions. The Mental Capacity Act should be followed in these cases, which states that the treatment of adults who are deemed not to have capacity regarding treatment decisions, should be in their best interests and necessary.

Annual Health Check

Everyone with learning disability should have an annual health check carried out in their GP surgery. This will include assessment of:

- Weight, Height, Blood Pressure and Pulse rate
- Communication needs
- Medication review
- Lifestyle factors such as smoking, exercise and substance use including alcohol
- Vision and Hearing
- Immunisations
- Mobility
- Foot care
- Continence
- Well man awareness – prostate and testicular health
- Well woman awareness
- Sexual health
- Health conditions
- Mental health and emotional conditions

People with learning disability should receive

- Influenza and pneumococcal vaccination
- Cervical and Breast cancer screening for females

Additional checks for people with Downs Syndrome may include:

- Thyroid function tests annually
- Hearing and visual tests and examination of ears
- Cardiovascular examination
- Sleep / daytime somnolence and throat examination
- Neck examination
- Mood/anxiety symptoms

Mental Health in Down's syndrome

Adolescents, as well as young adults with DS may present with increased vulnerability to:

- Depression, social withdrawal, diminished interests, and coping skills
- Generalized anxiety
- Obsessive compulsive behaviours

- Neurodevelopmental conditions such Attention Deficit Hyperactivity Disorder
- Regression with decline in loss of cognitive and social skills
- Chronic sleep difficulties, daytime sleepiness, fatigue, and mood related problems

Older adults present with increased vulnerability to:

- Generalised anxiety
- Obsessive compulsive symptoms
- Depression, social withdrawal, loss of interest, and diminished self-care
- Regression with decline in cognitive and social skills
- Dementia
- Other mood disorders

Mental disorders can present with a decline of skills and may be mislabelled as dementia. Depression is often responsive to treatment and therefore differentiating the two is essential. The more common symptoms in depression include withdrawal, deceased appetite and decrease in speech.

A useful checklist for assessing someone with DS is shown below and can be used by professionals and carers. This can identify symptoms or support a referral to specialist services (See 'Referral to Learning Disability services'- page 33).

Mental State Checklist
• Challenging behaviours including aggression, demanding, self-injury etc. • Low mood and tearfulness, diminished interests and social withdrawal • Increase in obsessive/ritualistic/repetitive behaviours • Bizarre behaviour, distracted, paranoid and agitated behaviour • Speech - reduced and/or less communicative • Sleep disturbances • Receptive communication impaired, loss of skills, confusion, wandering and memory problems • Any change in behaviour may indicate a physical health problem such as infection, environmental causes such as change of home or carers, problems with communication or mental health problems and dementia.

Ageing in Down's syndrome

Alzheimer's Dementia

Dementia is much more common in people with DS and occurs much earlier. The prevalence of Alzheimer's disease has been estimated to be 3.4% for people in their 30s, 10.3 in the 40s and 40% in the 50s, 56% for those 60 and over and mean age of onset is 52.8 yrs.

Clinical presentation of dementia can occur as early as aged 30, but is more likely to occur after 40 years and the peak incidence is in the early 50's. Many people first present with behavioural changes rather than cognitive decline, but memory and orientation can also be affected early on.

Professionals should enquire about features of dementia from age 30 onwards and any symptoms may indicate that a referral to specialist services may be required. **The Adaptive Behaviour Dementia Questionnaire (ABDQ)** (Prasher at al. 2004) can be found in **Appendix 8a**. It is a 15-item questionnaire which can be used to detect change in adaptive

behaviour, and compares information on previous level of functioning. This can be used be professionals to ascertain whether referral to services is indicated. (See 'Referral to Learning Disability services'- page 33).

The Plymouth Dementia Screening Checklist (Whitwham et al. 2010) is a useful tool for staff to use to determine whether or not to make a referral for a dementia assessment. The checklist has three areas for recording negative changes - behaviour, mood and memory, which are consistent with the literature in terms of likely areas of deterioration in the early stages of dementia **(Appendix 8b).**

When to consider the possibility of dementia in adult with Down syndrome

- Changes in behaviour or personality (commonly seen early on in dementia in Down syndrome)
- Memory problems
- Change in mood such as depression
- Challenging behaviour
- Loss of skills e.g. communication, self-care, relationships etc.
- New onset of seizures or other neurological symptoms

Assessment and Treatment

- Ensure a thorough physical examination is undertaken and any physical or mental health problems identified treated appropriately.
- The following Blood tests are recommended in an individual with LD when dementia is suspected
    - Full blood counts
    - Urea and Electrolytes
    - Blood Glucose (Fasting Blood Sugar is ideal)
    - Liver and Thyroid Function Tests
    - B12 and Folate levels
    - Lipid profile
    - Other blood tests as indicated by the physical examination and history
- Sensory screening – vision and hearing.
- Consider psychosocial causes (bereavement, abuse etc.) and environmental changes.
- The doctor assessing the person with Down syndrome for dementia will need to decide whether to offer to refer for a brain scan such as CT or MRI. Brain scans are recommended by NICE (The National Institute for Health and Care Excellence) to exclude other brain pathologies and to help determining the type of dementia. This may be less useful in Down syndrome, and it is recommended only to "rule out" other pathology as the atrophy seen in Alzheimer's disease is also seen in people with Down syndrome who are not dementing. Vascular dementia is less likely to occur in persons with Down syndrome.

Epilepsy in dementia

- Up to 90% of people with Down syndrome and dementia develop epilepsy
    - It can be present before the onset of the dementia, the presenting symptom of dementia, or develop later on in the illness
    - Seizures can include myoclonus, tonic-clonic seizures and partial seizures
- People with Down syndrome diagnosed with dementia and their carers need information on the likelihood of developing seizures as well as more general information about dementia
- If seizures should occur:
    - Refer to a learning disability psychiatrist for advice and treatment
- Take the presence of seizures into consideration when making a care plan or end of life plan for someone with dementia

- Management of myoclonus may be part of the palliative care of a person dying from dementia if the myoclonus is causing distress or discomfort

The Adult Learning Disability Service

For adults with a learning disability we provide support from community based teams, inpatient treatment as well as short-break services. We also offer specialist advice and support to those involved in caring for someone with a learning disability.

We provide a range of services to meet the specialist health needs of People with Learning Disabilities that include support for mental health problems, epilepsy, challenging behaviour, complex physical disabilities, eating and drinking and communication. We have been developing care pathways for different conditions including:

- Mental Health
- Eating and Drinking
- Challenging Behaviour
- Epilepsy
- Dementia
- Complex Physical Disability
- Forensic
- Autism

Community teams provide a range of professional services and include Psychiatrists, Psychologists, the Outreach team, Community Nurses, Social Workers, Occupational Therapists, Physiotherapists and Speech & Language Therapists. The aims of these teams are:

- To provide evidence based specialist interventions for people with the most complex needs
- To build capacity and capability across mainstream services and communities in order to reduce health inequalities

We also have an inpatient unit, a short breaks service and an autism specialist service.

Acute Liaison Nurses

The service exists to promote access to hospital services for people with learning disabilities by directly supporting people, developing hospital and community systems, influencing strategies and policies, and educating hospital staff.

The Learning Disability Acute Liaison Nurse can assist with co-ordination of care, support and advice for acute care staff in relation to personalised care and service delivery, collaboration between the agencies involved in service delivery, promotion of effective communication with those involved in the patient's, support of a relative or a family member with a learning disability who is affected by the patient's illness/ hospital stay, provide accessible information about treatments and promote positive experiences and outcomes.

Primary Care Liaison Nurses

The Primary Care Liaison Nurses takes a lead role in developing, co-ordinating and facilitating high quality service for people with learning disabilities accessing the GP. They can provide advice and support to primary care workers such as general practitioners and nurses, and to patients and carers. They also work with partner agencies to aid development and improvement of access to primary care services for people with a learning disability and address the health inequalities which can be experienced by people with a learning disability.

Referral to Learning Disability Services

Referral and discharge criteria for the adult learning disability team and the different sub-specialities are based on the clinical care pathways.
Patients referred should

- be 18 years or older
- have a learning disability
- have a health need (see below)

Health needs in Learning Disability

- Challenging Behaviour causing risks to self or others, or preventing access to day-care
- Suspected mental health problem not responding to treatment in primary care (anxiety disorders and affective disorders more commonly)
- Epilepsy – Seizures difficult to control in primary care or new onset of seizures
- Suspected dementia
- Suspected Autism affecting relationships, functioning or behaviour
- Forensic / Offending issues with associated mental health problems or challenging behaviour
- Difficulty with swallowing
- Falls
- Additional needs: autism friendly environment, sensory needs, meaningful daytime occupation, mobility deterioration, communication passport, support with physical health check/phlebotomy, nutritional and enteral nutrition.

The referral form can be found in **Appendix 9.**

The Stopping Over Medication of People with learning disabilities and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP)

Launched in December 2018 by NHS England and The Royal College of Paediatrics and Child Health, the STOMP/STAMP initiative aims to ensure that medication is prescribed appropriately and in accordance with the NICE guidelines which were drawn as a result of the Winterbourne View Hospital report by the Department of health.
This initiative calls for a review, reduction or stopping of psychotropic drugs in people with a learning disability, autism or both and principles of dose reduction and drug discontinuation. It lays down specific reasons for starting psychotropics in people with learning disability such as, ineffectiveness of psychological and/or other interventions, treatment for coexisting mental or physical conditions, or substantial risks of injury. The algorithm also highlights the importance of documenting the exact indications for starting the psychotropic medication and continuing monitoring of the response and development of side-effects.

People with Down Syndrome who are referred to the Learning Disability Services and are prescribed with psychotropics for management of mental health disorders, behaviours that challenge, or both, should undergo a STOMP review annually along with their annual health check to minimise the adverse effects of the medication.

An algorithm for this review published by the National Institutes for Clinical Excellence (NICE) can be found here - https://www.england.nhs.uk/wp-content/uploads/2017/07/stomp-gp-prescribing-v17.pdf

Social Services and Support Groups

The Leicester City and Leicestershire County Social Services can offer support for people with learning disabilities **to develop skills and have choice and control over their lives.**

The Downs Syndrome Association is useful resource for information and support - **http://www.downs-syndrome.org.uk/**

Appendix 1 - Conditions Occurring More Commonly in People with Down's syndrome

Cardiac

- Congenital malformation
- Cor Pulmonale
- Acquired valvular dysfunction
- Children without congenital heart disease can develop heart problems at a later age
- Referral to cardiology in early adult life should be considered

Cervical spine

- X-Ray is no longer recommended as not informative – i.e. has no predictive value if normal
- Neurological symptoms normally precede incidents of major trauma
- Radiological screening is not indicated and sporting activities should not be restricted in those with no clinical signs
- Particular care should be taken when manipulating the head of an unconscious child and anaesthetists and ambulance personnel should be alerted
- All carers and clinicians should be aware of the warning signs:
  - Abnormal head posture or torticollis
  - Restricted neck movement / pain behind the ear
  - Neck pain
  - Altered gait
  - Deteriorating manipulative skills
  - Deterioration in bowel or bladder control
- Clinical symptoms which are often mild are currently the most useful predictors of future risk and merit urgent specialist referral

Dermatological

- Dry skin
- Folliculitis
- Vitiligo
- Alopecia

Endocrine

- **Obesity** is not inevitable and should always be thoroughly assessed.
- **Thyroid dysfunction -** prevalence increases with age (Uncompensated hypothyroidism in about 10% of school age population)
- **Diabetes type 1** Probably around 10 times more common as in other children

ENT

- Over 50 % have some hearing loss; either Conductive and/or Sensorineural
- Upper airway obstruction
- Chronic Catarrh

Gastrointestinal

- Congenital malformations
- Feeding difficulties
- Gastro-oesophageal reflux
- Hirshprung's disease
- Coeliac disease- have low threshold of clinical suspicion
- Screen all with major or minor symptoms as follows:
  - Disordered bowel function tending to diarrhoea or to new constipation

- Failure to thrive as indicated using Down's syndrome specific reference charts
- Abdominal distension
- General unhappiness and misery
- Arthritis
- Rash suggesting dermatitis herpetiformis
- Existing type 1 diabetes, thyroid disease or anaemia

- If antibody screen positive, or negative but significant symptoms, refer for small bowel biopsy

Growth

- Feeding difficulties often lead to failure to regain birth weight until 1 month of age.
- Children with Down's syndrome are at greater risk of conditions that can result in poor growth e.g.congenital heart disease ; sleep related upper airway obstruction; coeliac disease; nutritional inadequacy due to feeding problems; and thyroid hormone deficiency.
- Rapid weight gain should prompt check of Thyroid function
- Children <2nd centile who do not have a known clinical explanation should be evaluated.

Immunological

- Immunodeficiency * Children with Down's syndrome should be eligible for annual flu vaccination(See current immunology guidelines- appendix 7)
- Autoimmune diseases e.g.. arthropathy, vitiligo, alopecia

Haematological

- Neonatal polycythaemia occurs in >60% of neonates
- Neonatal thrombocytopenia
- MCV increased at all ages
- Transient Abnormal Myelopoesis (TAM)
  - Approx 25% of children with TAM may develop acute myeloid leukaemia (AML) later in childhood

Leukaemia

- 20 times more frequent than other children.
- Risk approx 1/100
- Peak age of onset <4 years

Musculoskeletal

- Hypotonia, ligamentous laxity and skeletal dysplasias may predispose to other orthopaedic problems
- Intervention may be needed if pain, limited function or risk of structural damage

Neuropsychiatric

- Infantile spasms and other myoclonic epilepsies
- Autism
- Depressive illness
- Dementia (adults only)

Ophthalmic

- Refractive errors
- Nasolacrimal obstruction
- Cataracts
- Glaucoma
- Keratoconus
- Squint

- Nystagmus
- Blepharitis

Orthopaedic
- Cervical spine instability
- Hip subluxation/dislocation
- Metatarsus varus
- Patellar instability
- Pes planus
- Scoliosis

Respiratory
- Lower airway and upper airway problems
  - 65-80% of children have nocturnal hypoventilation and/or decreased oxygen saturation
- Obstructive sleep apnoea (OSA)
  - 60% of children
  - sleep disturbance, snoring, chest wall recession' abnormal sleep postures and frequent nocturnal arousals.
  - May lead to life threatening acute obstructive events particularly if given sedation for any reason.
  - Screen for OSA symptoms with sleep questionnaires/ sleep history at every clinic review from 6 month onwards
  - Refer for sleep studies at 3 -4 years of age or earlier if symptoms of OSA
  - If symptoms of OSA, please refer to ENT and sleep service

- nasal congestion
- swallowing difficulties

Vision
- There is a high prevalence of ocular disorder among people with Down's syndrome.
- Refractive errors and/or squint may be present from an early age and persist into childhood
- The majority of children with Down's syndrome have reduced accommodation
- Tenfold increase in congenital cataract
- Infantile glaucoma may occur
- Nystagmus is present in at least 10% (8) .
- Cataracts and keratoconus may develop in teenage years or later and studies suggest that these are approximately 4 times more common than in the adult general population
- Blepharitis may occur in up to 30% of children
- Nasolacrimal duct obstruction also occurs commonly and may need specialist referral

References:

- Textbook of neonatology – Rennie/Roberton
- The Down's syndrome Medical Interest group – www.dsmig.org.uk
- This website contains basic medical surveillance essentials for people with Down's syndrome with detailed references for each system.

Appendix 2 – Obstructive Sleep Apnoea

Obstructive Sleep Apnoea	**University Hospitals of Leicester NHS Trust** NHS **Children's Sleep Service** **Parent, Carer and Patient Fact Sheet**

What is Obstructive Sleep Apnoea?

- Obstructive Sleep Apnoea (OSA) is the term used for obstruction to breathing during sleep. This obstruction when severe may cause the person to stop breathing, but when less severe can result in increased resistance to breathing. They will both cause interruptions in the persons sleep by causing them to waken or to experience fragmentation (breaks) in their sleep pattern.

- The upper airway is the part of the breathing system between the nose and the vocal cords. The nose is supported by bone and airways from the vocal cords downwards are supported by cartilage, but the throat is a muscle tube. As the muscle tube of the throat is not supported by rigid tissues, it is this area where patients with OSA will experience obstruction.

- When we sleep our muscles relax, but the passage remains open enough to permit the flow of air. In children with OSA, the relaxation of these muscles causes the passage to close momentarily and air cannot get passed or has difficulty passing.

- Although snoring is a prominent symptom of OSA, its presence does not mean that a child has OSA. Snoring can occur without OSA. About 15 children in every 100 snore, but only 1 or 3 of those will have symptoms of OSA.

What are the symptoms?

Children will have night time and day time symptoms:

<u>Night time:</u>
- Restless sleep – the child may not get out of bed but will move around in bed excessively and kick his or her covers off
- Loud snoring, occasionally interrupted by silence and gasps,
- Mouth breathing when asleep,
- Excessive sweating when asleep.

<u>Day time:</u>
- Tired in the morning – difficult to get out of bed,
- Excessive day time sleepiness,
- Poor concentration at school, restless and fidgety
- Irritable and moody.

Causes

- Enlarged Tonsils and Adenoids. The commonest cause of OSA in children. They are at their biggest in relation to the size of the child's face between 2 and 7 years of age. They become enlarged as they are lymphoid tissue and enlarge in response to infections, and pre-school children have lots of upper respiratory infections ('Coughs and colds'). Having the tonsils and adenoids out cures OSA in 80-90% of children.

- Obesity.

- Long-term allergy or hay fever. This can usually be treated.

- Certain conditions with weak muscles or low muscle tone, e.g. Down syndrome.

- Individuals with Down syndrome have OSA due to common anatomic abnormalities (macroglossia, enlarged tonsils and adenoids, mid face hypoplasia) and other associated conditions such as obesity, hypothyroidism, hypotonia, and gastroesophageal reflux.

Treatment

- Depends on the cause – and may be cured if that cause is treated.
- OSA may persist despite removing the cause, and is then best treated with nasal CPAP (Continuous Positive Airways Pressure) where low pressure air is blown by a machine through a nasal mask into the nose keeping the airway open.

Appendix 3 - SPA Form

Please Note: Fields marked '*' are **mandatory**. Any SPA forms returned with one or more of these fields incomplete will be automatically rejected and returned to referrer.

*Forename of child :	*Surname of child :	*Referrer name : Designation :
*D.O.B.	NHS No / *Gender	*Address :
*Address :	Postcode	*Tel No. :
*Parent's / carers names :	*H	*M / W

*Who has parental responsibility for child?

As Above ☐ Other ☐ (If "Other", please provide details) _____

How long have the family lived in the UK?

Home Languages (Including English) _____ Written ☐ Spoken ☐ _____ Written ☐ Spoken ☐

Please *cross* if interpreter is needed ☐

*Principle Reason for Referral :

Other information to support reason for referral; *In order to process this referral appropriately please specify the following:*

- Nature of Concern :
- How long these problems have been evident :
- If the child is experiencing functional / developmental / behavioural difficulties please state the child's current abilities and difficulties (eg, how do these difficulties affect the child at school/nursery/home) :

I consent to the above referral and any assessment that may be required. I consent to information being shared with the appropriate statutory agencies as long as it is in the best interest of my child

Name and signature of Parent / Carer _____

*Verbal consent obtained from parent by referrer? Yes ☐ No ☐

For help completing this referral please refer to the SPA guidelines available from http://website.leicschildhealth.nhs.uk/_Resources-ReferralCriteria.aspx, or alternatively contact the Children's Disability Service Helpline, Monday-Friday 12-2pm on 0116 225 6560

Have any diagnoses already been made? Please detail by whom and when:
List courses of action tried to date and please state by whom?
*Are any other services currently involved? Please provide contact telephone numbers where possible
Which school does the child attend?
Does the child have Special Educational Needs? Yes ☐ No ☐ Please cross as appropriate Action ☐ Spoken ☐ Written ☐
Are any of the following in place for the child (if so please provide copies): Common Assessment Framework (CAF) Yes ☐ No ☐ Child in Needs Support Yes ☐ No ☐ Child Protection Plan Yes ☐ No ☐ Is the child a Looked after Child? Yes ☐ No ☐ If so please provide details of social worker in the space allocated above
Views of child / parent or carer :

*Signature of professional completing referral :	Date of referral : Thursday, 03 November 2011

Please return this form, along with any relevant additional information, to:

Single Point of Access, Leicester, Leicestershire & Rutland, Children's Community Health Service

Bridge Park Plaza, Bridge Park Road, Thurmaston, Leicester, LE4 8PQ

Tel: 0116 225 2525 Fax: 0116 2958302

Appendix 4 - Medical Checklist

Age	Birth	6 wks	3 mnth	6 mnth	1 year	2 years	3 years	4 years	5 years	6 years	7 years	8 years	9 years	10 years	11 years	12 years	13 years	14 years	15 years	16 years	17 years	18 years
Guthrie result																						
Genetics result																						
Cardiac assessment																						Consider
Red book insert given																						
Info re DSA given																						
Venepuncture T4, TFTs thyroid antibodies				4-6 months																		
Plot growth in Down's chart																						
Check for cervical spine symptoms																						
Referral to orthoptics																						
2 yearly vision test																						
Review visual behaviour/vision																						
Referral to audiology ASAP																						
Hearing check				8-10 months	15-18 months																	
Notified to education authority																						
Transition plan																						

Appendix 5 - UHL Discharge Checklist

Neonatal Checklist for Babies with Down's Syndrome	University Hospitals of Leicester NHS NHS Trust *Sept 2017 – Sept 2019*

Scope
This guideline is aimed at all Health care professionals involved in the care of infants within the Neonatal Service.

Legal Liability (standard UHL statement)
Guidelines issued and approved by the Trust are considered to represent best practice. Staff may only exceptionally depart from any relevant Trust guidelines providing always that such departure is confined to the specific needs of individual circumstances. In healthcare delivery such departure shall only be undertaken where, in the judgement of the responsible healthcare professional, it is fully appropriate and justifiable - such decision to be fully recorded in the patient's notes

Key Points

- Both the checklist and referral form need to be completed for all children with confirmed or suspected Down's syndrome before discharge from the neonatal unit or postnatal ward.

- Neonatal management of Down syndrome includes clinical assessment, referral to specialist services (community child services and cardiology) and providing parents with appropriate information.

Related UHL documents

Document	ID Number (if applicable) or Appendix No.
Care Pathway for Children with Down's Syndrome: Birth to 19th Birthday	LLR Hospital & Community Services overarching policy

Aim

Pages 3 and 4 (based on Appendix 3 and Appendix 5 of the Down Syndrome Care Pathway) provide a printable version of the checklist and referral forms that need to be completed for **all** children with confirmed or suspected Down's syndrome before discharge from the neonatal unit or postnatal ward.

UHL Discharge Checklist

Neonatal Checklist for Babies with confirmed or suspected Down's Syndrome

ALL FIELDS MUST BE COMPLETED PRIOR TO DISCHARGE.
Tick Box when complete

Clinical Assessment

1. ECG performed. ❑
2. Oxygen saturations measured (pre- and post-ductal). ❑
3. Ensure baby has opened his / her bowels. ❑
4. Ensure feeding is established. ❑

Referrals

5. If referral to infant feeding coordinator is required has this been done? ❑
6. Has a referral been made to the Community Paediatric services (FYPC -Families, Young People and Children's Services referral)? ❑
7. Has a Neonatal Follow Clinic (neonatal consultant) been arranged? ❑
8. Has referral to Paediatric Cardiology been made?
   - for review within 1 week of birth. ❑

Information

9. Ensure parents have been given adequate information regarding Down's Syndrome. ❑
10. Offer parents the Down's Syndrome Association booklet 'A New Parent's Guide' . ❑
11. Ensure the Down's Syndrome specific growth charts are in the Child Health Record ❑

PLEASE FILE CHECKLIST IN HOSPITAL MEDICAL RECORDS.

Leicestershire Partnership
NHS Trust

FAMILIES, YOUNG PEOPLE & CHILDREN'S SERVICE REFERRAL FORM

Forename of child	Surname of child

Parent's names

Address

Postcode

School/Nursery

How long have the family lived in the UK?

Contact Numbers	Gender
	Male ☐ Female ☐

NHS Number	Date of Birth

Referrer Name

Designation

Address

Telephone Number

Fax Number

Languages Spoken	Languages Read	Is interpreter needed
		Yes ☐ No☐

Referral information

Which services\pathway do you consider are needed

State if mental health needs requiring assessment by CAMHS

Principle reason for referral

Nature of concern

FAMILIES, YOUNG PEOPLE & CHILDREN'S SERVICE REFERRAL FORM

Any additional information that you feel is relevant?

(Please attach relevant documentation & reports)

Other professional's \ services currently involved with the family?

(Please provide details of relevant previous input as well if available)

Any Safeguarding concerns?

Yes ☐ No ☐ Not known ☐

(If yes please specify with details of Social Worker if Known)

Any Special Education Needs

Yes ☐ No ☐ Not known ☐

(If yes please specify)

Please record if the patient has given consent to access information recorded via the SystmOne Electronic Record System.

(please note referrals cannot be processed without consent obtained)

Consent given ☐ Dissent given ☐ Consent obtained on patient's behalf ☐

Views of child/parent or carer: *(optional)*

Signature	**Date**

Once completed please return form to us by:

Email:	fypc.referrals@nhs.net	**Fax:** 0116 2958302
Post:	FYPC Referrals. Families, Young People and Children's Services, Leicester Partnership NHS Trust, Bridge Park Plaza, Bridge Park Road, Thurmaston, Leicester, LE4 8PQ.	

Where possible please complete the form electronically, if completing by hand please use additional sheets if needed. For more information view www.leicspart.nhs.uk/fypcreferrals.

References

Care Pathway for Children with Down's Syndrome: Birth to 19th Birthday
LLR Hospital & Community Services overarching policy 2012

Auditable standards

1. A paediatric cardiology appointment should be made with review arranged for within a week post-delivery (100%).
2. A referral to the Community Services should be made for all infants with confirmed or suspected Down's syndrome (100%).

Guideline development:

March 2012	Care Pathway for Children with Down's Syndrome: Birth to 19th Birthday LLR Hospital & Community Services overarching policy 2012 Reviewed on behalf of the neonatal service by A. Currie
June 2016	Printable version of UHL neonatal Down syndrome checklist and FYPC community services referral form compiled
Sept 2017	Reviewed against most recent Down syndrome pathway (REM). No amendments required,

Appendix 6 - LNDS referral form

Paediatric Referral

Leicestershire Nutrition and Dietetic Service NHS

PAEDIATRIC DIETETIC REFERRAL FORM – PRIMARY HEALTH CARE OUTPATIENTS

Please note this form should be posted or FAXED. Please DO NOT send electronically.

FROM: Name ..... Job Title.....

Referrers Correspondence Address .....

.....Tel No.....Fax.....

To: Leicestershire Nutrition and Dietetic Service, 11/12 Warren Park Way, Enderby, Leicester LE19 4SA

Fax: 0116 272 7228 **Telephone: 0116 272 7200**

DATE OF REFERRAL:	NHS NO:	CHILD'S SURNAME: FORENAME/S:	
GP NAME AND ADDRESS:		CHILD'S ADDRESS: POST CODE:	
PARENT/CARER NAME AND DAYTIME CONTACT NUMBER **(please provide if available)**		SEX: M / F	DATE OF BIRTH:
KEY HEALTH PROFESSIONAL/HEALTH VISITOR NAME AND CONTACT DETAILS:		*WEIGHT (kg): CENTILE:	*HEIGHT (m): CENTILE:
SPECIAL REQUESTS (e.g. Language/Interpreter)		BMI: (=kg/m^2)	
REASON FOR REFERRAL **(please complete in conjunction with mandatory boxes marked *)**		Other relevant information: -Child development needs .... -Key health and social care workers involved..... .... -Has a Child Protection Plan ...YES/NO - Relevant biochemistry.....	
RELEVANT MEDICATION			
RELEVANT MEDICAL/SOCIAL HISTORY: Child registered with Cons. Paediatrician at Special Community Child Health Services YES/NO			
DIET SUGGESTED:			

INCOMPLETE REFERRALS MAY BE RETURNED **AUGUST 2008**

If you have access to PRISM, please use PRISM referral

Appendix 7- Immunology guidance for children with Down's syndrome

Reviewed January 2023 in conjunction with Dr R Radcliffe Consultant Paediatrician UHL taking into account national Down's Syndrome Medical Interest Group guidance.

Background

Children with Down's syndrome have a greater risk of both infection and increased severity of those infections.

Multiple factors contribute to this:

- Impaired immunity (variable and multiple abnormalities: which may be, but not always, picked up with routine tests, usually mild)
- Medical co-morbidities eg cardiac disease, gastro-oesophageal reflux
- Anatomical differences eg mid-face hypoplasia, macroglossia, tracheobronchomalacia, small lower airway volume
- Other e.g. Hypotonia, obesity

Consequence:

- Prolonged or increased severity of infection (viral and bacterial)
- Recurrent infection
- Increased risk of ARDS

Current research in children/adults with Down Syndrome and Covid-19 shows that older children/adults are found to be more susceptible to severe disease. Vaccination is recommended for at risk groups as per national guidance and treatments such as monoclonal antibodies may also be available. Please check latest national guidance for specific antiviral and antibody treatments relating to covid-19 infection

Guidance

1. All children with Down's syndrome should have an alert placed on their GP and hospital records suggesting prompt use of and lower threshold for prescribing antibiotics when presenting with possible sepsis
2. Discuss history of infections at every review appointment.
3. Check for risk factors as above and carry out immune function tests if:
    a. 4 or more infections over a 6 month period requiring a visit to the GP
    b. Episodes of prolonged illness ie more than 5 days
    c. Hospital admission for sepsis
    d. Unusual infections (microbiological evidence of infection is helpful)
4. Baseline Immune function testing:
    a. Total Immunoglobulins
    b. Lymphocyte subsets (including on the form the information that child has Down's syndrome and the infection pattern)
    c. FBC
    d. Consider Hib, Tetanus and pneumococcal vaccine responses if history of significant bacterial infection (esp, Sinopulmonary) and fully vaccinated to 1 year immunisations. Discuss with paediatric immunology if unsure (**paedsimmunology@uhl-tr.nhs.uk**)

    Please see UHL guideline on investigations and interpretation

https://secure.library.leicestershospitals.nhs.uk/PAGL/Shared%20Documents/Primary%20Immunodeficiency%20-%20Suspected%20UHL%20Childrens%20Medical%20Guideline.pdf

5. Management
   Antibiotics:
   a. Advise the use of prompt antibiotic treatment, especially in children who meet the criteria in **point 3** including those children where immune function testing does not show abnormality
   b. Advise extended course of antibiotic treatment (10 – 14 days) in children who meet the criteria in **point 3** including those children where immune function testing does not show abnormality
   c. Consider prophylactic antibiotics (with change of antibiotic for breakthrough infections) in those struggling with repeated infections. (Suggest either Trimethoprim, 2mg / kg once daily, or Co-trimoxazole, single daily dose based on BNFc recommended dose for age; consider use of prophylactic antibiotics from September to April where infections are mainly in winter months). Review ongoing need for prophylactic antibiotics at each visit. If stopping, suggest to do this in late spring / early summer.

   Vaccinations
   a. Maximise immunity by ensuring child has had all appropriate vaccinations. **https://www.gov.uk/government/publications/the-complete-routine-immunisation-schedule**
   (Caution for use of live vaccines if on chemotherapy, immunosuppressive therapy or known to immunology services – discuss with relevant clinician)
   b. Consider if the child has other risk factors which would make them eligible for Pneumovax II at 2 years of age.
   https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857267/GB_Chapter_25_pneumococcal_January_2020.pdf
   c. Ensure child (from 6 months) and household members have annual influenza vaccination. Most children aged 2-18 years can receive the live nasal influenza vaccine (LAIV), which offers better protection. If receiving chemotherapy, immunosuppressive medication or known to immunology services, discuss with relevant clinician. Check here for other contraindications: **https://www.gov.uk/government/publications/influenza-the-green-book-chapter-19**
   d. Covid-19 vaccination is recommended for patients and their families as per national guidance.

Consider referral to paediatric immunology team for patients still experiencing infections in spite of above steps. (For advice on test results or referral, contact **paedsimmunology@uhl-tr.nhs.uk** in the first instance)

Guidelines for management of immune function in children with Down's syndrome

Michael Browning Consultant Immunologist LRI.
Written July 2015
Reviewed August 2018

Ruth Radcliffe Consultant Paediatrician LRI
Reviewed January 2023

Appendix 8a - ABDQ

THE ADAPTIVE BEHAVIOUR DEMENTIA QUESTIONNAIRE (ABDQ)

Screening instrument to detect dementia in Alzheimer's disease in adults with Down syndrome and other intellectual disabilities

2004

by

V.Prasher
(vprasher@compuserve.com)

The Greenfields, Monyhull,Monyhull Hall Road
Kings Norton, Birmingham, UK B30 3QQ
and
R Holder and F.Asim

Department of Statistics, University of Birmingham
Birmingham UK B15 2TZ

Prasher,V.P., Asim, F., Holder, R (2004). The Adaptive Behaviour Dementia Questionnaire (ABDQ) : Screening Questionnaire for Dementia in Alzheimer's disease in Adults with Down syndrome Research in Developmental Disabilities, 25(4):385-97.

BACKGROUND

An association between dementia in Alzheimer's disease and Down syndrome is well established. However, the clinical diagnosis and ongoing monitoring of the dementing process can at times be difficult. Direct cognitive testing is often not possible due to the underlying severity of intellectual disability, poor cooperation, impaired sensory function, presence of co-morbid illnesses and inability to detect accurately all areas of intellectual functioning.

The authors have been assessing changes in adaptive behaviour in adults with Down *syndrome* for more than 10 consecutive years. Adaptive behaviour can be assessed in all adults with intellectual disability (and especially in those with dementia) and overcomes many of the problems mentioned above regarding the use of cognitive based measures.

The authors with the analysis of consecutive adaptive data developed an informant- based clinical screening tool for dementia in Alzheimer's disease in adults with Down syndrome. The Adaptive Behaviour Dementia Questionnaire (ABDQ) is a 15-item questionnaire, derived from the AAMD Adaptive Behavior Scale (Nihira et al, 1974*) which is used to detect change in adaptive behaviour. The ABDQ has good reliability and validity, with an overall accuracy of 92%. Unlike other tests which can only determine the presence of dementia, the ABDQ has been developed to specifically to screen for dementia in Alzheimer's disease.

(*Nihira, K., Foster, R, Shellhaas, M., Leyland, H. (1974). AAMD Adaptive Behaviour Scale, 1974 Revision, American Association on Mental Deficiency, Washington, D.C.)

INSTRUCTIONS FOR COMPLETING THE ABDQ

To be completed by:-

i) interview with caregiver who is familiar over many years with the observed person
ii) an interviewer who has experience working with adults with intellectual disability

The questionnaire sets out to collect information on how the observed person **compares** *now* to their previous *normal* (usual) level of social functioning. By "normal" we mean when the person was in good health and BEFORE the onset of any recent problems suggestive of dementia. The term "normal" is used in each question.

Interviewers can use the client's name to make the questions more personal.

If never been able to perform question mark as "same as normal".

The ABDQ is designed to detect CHANGE in clinical status over time.

THE ADAPTIVE BEHAVIOUR DEMENTIA QUESTIONNAIRE (ABDQ)

Name:_____ Date of Birth:_____

Carer interviewed:_____

Completed by:_____ Date completed:_____

Please answer ALL questions by simply underlining the answer which you think most closely applies to the question. Please read instructions on how to complete ABDQ before filling in questionnaire

	Question	Answer			
1.	Are they able to dress themselves?	Better than normal	Same as normal	Worse than normal	Much worse than normal
2.	Can they use their hands to do things?	Better than normal	Same as normal	Worse than normal	Much worse than normal
3.	Is their ability to buy things?	Better than normal	Same as normal	Worse than normal	Much worse than normal
4.	Are they able to have a conversation?	Better than normal	Same as normal	Worse than normal	Much worse than normal
5.	Is their awareness of time?	Better than normal	Same as normal	Worse than normal	Much worse than normal
6.	Do they help to prepare food?	More than normal	Same as normal	Less than normal	Much less than normal
7.	Do they help to clear the table?	More than normal	Same as normal	Less than normal	Much less than normal
8.	Are they able to perform simple jobs?	Better than normal	Same as normal	Worse than normal	Much worse than normal
9.	Can they initiate things/activities?	More than normal	Same as normal	Less than normal	Much less than normal
10.	Is their ability to persist in doing things?	Better than normal	Same as normal	Worse than normal	Much worse than normal
11.	Can they take care of their belongings?	Better than normal	Same as normal	Worse than normal	Much worse than normal
12.	Do they cooperate with requests?	More than normal	Same as normal	Less than normal	Much less than normal
13.	Do they carry out simple commands?	Better than normal	Same as normal	Worse than normal	Much worse than normal
14.	Do they participate in group activities?	More than normal	Same as normal	Less than normal	Much less than normal
15.	Is their ability to do things independently?	Better than normal	Same as normal	Worse than normal	Much worse than normal

See ABDQ SCORING SHEET to score answers

ABDQ SCORING SHEET

Scoring:-	
Better than normal	= 0 mark
Same as normal	= 1 mark
Worse/less than normal	= 2 marks
Much worse/less than normal	= 3 marks

A

(A= Sum of scores for questions 1,3,4,6,10,11,14,15)

B

(B= 3 multiplied by [Sum of scores for questions 12 & 13])

C

(C= 4 multiplied by [Sum of scores for questions 2,5,8])

D

(D=5 multiplied by score for question 9)

E

(E= 6 multiplied by score for question 7)

TOTAL SCORE

(TOTAL SCORE= A+B+C+D+E)

DEMENTIA IN ALZHEIMER'S DISEASE PRESENT YES NO
(Yes if Total Score is 78 or more)

SEVERITY OF DEMENTIA MILD MODERATE SEVERE
(Total Score is 78-89 = mild; 90-99 = moderate; 100 or more=severe)

Appendix 8b – Plymouth Dementia Screening Checklist

1. **Has there been a <u>negative change</u> in memory functioning over the past 12months?**
   For example: *Short-term memory problems? Repetitive in conversation? Needsfrequent reminding/ prompting? Concentration problems?*

No change ◄——————————————————► Extensive change

Points = □ 0 □ 1 □ 2 □ 3 **Total /3**

2. **Has there been a <u>negative change</u> in mood over the past 12 months?**
   For example: *Low in mood? Withdrawn? Mood swings?*

No change ◄——————————————————► Extensive change

Points = □ 0 □ 1 □ 2 □ 3 **Total /3**

3. **Has there been a negative change in behaviour over the past 12 months?**
   For example: *Difficult behaviours? Night wandering? Inappropriate behaviour? Aggression? Incontinence? Losing skills?*

No change ◄——————————————————► Extensive change

Points = □ 0 □ 1 □ 2 □ 3 **Total /3**

Have any other changes been noticed?
Please consider: Language and communication skills? Self-help skills? Activities of dailyliving?

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(Whitwham, S.; McBrien, J. & Broom, W. (2010) should we refer for a dementia assessment? A checklist to help know when to be concerned about dementia in adults with Down syndrome and other intellectual disabilities. British Journal of Learning Disabilities.)

Appendix 9 - Referral form for adult LD team

LEARNING DISABILITIES SERVICE (HEALTH)
REFERRAL FORM

Return completed forms to:
Learning Disability Access Team
138 Winstanley Drive
Leicester
LE3 1PB
Tel: 0116 295 4528

Confidentiality: People have a right to access information about themselves. Please advise the person you are referring that the information you give could be shared with other members of the Healthcare Team in order to give them the most appropriate services but that they have a right to withhold their consent. During the course of their care some information may be recorded on computers. For their protection, the use of this data is controlled in accordance with the Data Protection Act (2018).

Referral Criteria
A learning disability is defined by the Department of Health as a "significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood".

Eligibility Criteria:

- The patient has a **significant learning disability** and is aged 18 or over
- The patient has health difficulties which are critical or substantial in nature and that cannot be fully met via mainstream services
- The patient has complex health needs.

Exclusion Criteria (unless there is a learning disability)

- Dyslexia
- Dyspraxia
- Hyperactivity Attention Deficit Disorder (ADHD)
- Autism

If you would like to discuss your referral first, please contact the Learning Disability Access Team on 0116 295 4528.

Has the person referred got a diagnosis of learning disability? *please tick* YES ☐ NO ☐

If No, Why do you suspect a learning disability? Please give evidence below:

NB: If key information is not competed the referral may be returned and not progressed

Date of Referral		**NHS No:**	

Referred person:

Surname	**Forename(s)**	**DOB**	**M/F**	**Mental Health Act (MHA) Status** (if applicable)

Ethnic Origin		**Religion**		**Marital Status**	
Main Language		**Interpreter Needed**	☐ ***Yes*** ☐ ***No***		

Main Address		**GP Address**	
	Type of Accommodation?		**Is GP Aware of referral: Y / N**
Tel no:		**GP Tel No:**	

NB The registered GP must be part of a Leicester, Leicestershire or Rutland CCG practice for the referral to be accepted

Funding – who funds support received by this person e.g. CHC, Social Care, S117

Details of Next of Kin/Carers including the person they live with and who is responsible for their care?

Does the person have an independent advocate? ☐ ***Yes*** ☐ ***No*** ***If yes include their details below.***

Full Name	**Contact Number**	**Relationship to Client/ patient**	**Address if different to the clients**

Who is the best person to contact regarding the referral to gather pre assessment information?
✓Tick where appropriate and provide details below

Patient	Next of Kin	Main Carer	Other Professional

Are there any legal arrangements in place that the service need to be aware of? If yes please tell us what these are:

Referrer Details			
Name		**Telephone Number**	
Relationship to Patient			
Address			

Consent NB consent or a best interest's decision must be confirmed for the referral to be accepted
Is the Patient is able to make informed consent and has consented to the referral? Y / N **If NO, has best interest been considered: Y / N** **Details:**
Reason for Referral:
• **What has prompted you to make this referral now?** • **Please describe the current health situation, when it started including any recent changes/ life events that have occurred in the person's life:** • **How has this impacted on both the patient, their family or carer?** • **What improvement(s) would you expect to see as a result of this referral?** • **Has this client been seen by the service in the past Y/N/ Don't know**

Does the person present with any of the following? Tick any that apply.

- ☐ Challenging Behaviour /Positive Behaviour Support
- ☐ Difficulties eating and drinking safely
- ☐ Complex Physical Health needs
- ☐ Sensory impairment
- ☐ Forensic risks
- ☐ Drug and/ or alcohol, substance misuse
- ☐ Autistic Spectrum Disorder (ASD)
- ☐ Mental Health
- ☐ Epilepsy
- ☐ Dementia/ cognitive decline
- ☐ Other, give details.

Risks including Safeguarding

Are there any current safeguarding concerns: Y / N	
Details:	

Any risks known or reported when working with this person – this includes risk to the person themselves. Please give details:

Communication Issues: ☐ Yes ☐ No
Details:

Family or Friends: ☐ Yes ☐ No
Details:

Forensic / Police History: ☐ Yes ☐ No

Challenging Behaviour: ☐ Yes ☐ No

Physical Disability: ☐ Yes ☐ No

Home Environment: ☐ Yes ☐ No

Other (Please State):	☐ **Yes** ☐ **No**
Action already taken / Current plan and levels of support being offered:	

Current Professionals Involved (health, social care, private provider)		
Name	**Professional Role**	**Contact Details**

Appendix 10 – Physiotherapy Advice for Down's Syndrome

NHS
Leicestershire Partnership
NHS Trust

Physiotherapy Advice for Down's Syndrome

Local advice and information for parents of children with Down's syndrome

Physiotherapy Service
Bridge Park Plaza
Bridge Park Road
Thurmaston
Leicester
LE4 8PQ

Phone: 0116 295 2492

www.leicspart.nhs.uk

Email: lpt.feedback@nhs.net

Will my child need physiotherapy?

Most children with Down's syndrome have delayed motor development. They will usually achieve their motor milestones (e.g. rolling over, sitting, walking) but will do so at a slower pace. Therefore physiotherapy intervention is not usually necessary.

Some children with Down's syndrome may have greater difficulties with motor development and physiotherapy may be needed.

Physiotherapy may be needed if your child:

- is not able to hold their head up on their own at 8 months
- is unable to sit on the floor on their own with no support at 18 months
- won't take weight through their legs when placed in a standing position up against the sofa by the age of 2 years
- is not walking on their own by the age of 4 years (or by the time they start school)
- has additional problems with their spine that affect the way they lie, sit or move
- has additional problems with their heart that makes them extra tired or extra floppy
- is extremely floppy and not moving around much when up against gravity
- has other difficulties e.g. an additional diagnosis of another condition that has an impact on their movement.

If you are worried about any of these issues and would like to know if a physiotherapy referral is needed, please discuss this with your GP or Paediatrician who will advise you.

2

How can I help my child?

For activities to promote your child's motor and overall development see the Down's Syndrome Association 'New Parents Pack' which your Public Health Nurse (formerly Health Visitor) has given to you. Ask your Public Health Nurse for opportunities in your local areas e.g. groups to attend.

Once your child is walking, continue to encourage them to build up strength and stamina through daily activity that is meaningful, functional, fun and age appropriate.

Encourage your child to participate in suitable sports and leisure activities at their own level. If you have any concerns about your child participating safely in certain activities, discuss this with your Paediatrician who knows the medical needs of your child and can advise you accordingly. Promoting activity should continue throughout your child's life into adulthood.

Will my child need special equipment?

Usually children with Down's syndrome do not need special equipment but they may need specialist footwear.

When your child begins to stand, they may adopt an unusual foot position (usually the feet roll inwards). This may be helped by special boots or insoles provided by the orthotic department. Ask your GP or Community Paediatrician to refer you directly to the orthotic department where the foot position of your child will be assessed and appropriate support for your child's feet will be provided if necessary.

Once your child has received specialist boots or insoles you can contact the orthotic department directly for follow-up appointments.

3

Notes / any questions you may have

If you need help to understand this leaflet or would like it in a different language or format such as large print, Braille or audio, please ask a member of staff.

Opening times:

Monday to Thursday
8.30am - 5.30pm

Friday 8.30am - 4pm

Date implemented: October 2017
Last reviewed: May 2023
Review date: May 2025
Leaflet No. 468 - Edition 3

Appendix 11 Children's Occupational Therapy Service

NHS
Leicestershire Partnership
NHS Trust

Children's Occupational Therapy Services

Patient information leaflet

Bridge Park Plaza
Bridge Park Road
Thurmaston
Leicester
LE4 8PQ

Phone: 0116 295 2495

www.leicspart.nhs.uk

Email: lpt.feedback@nhs.net

What is occupational therapy?

The Children's Occupational Therapy Team help children who have difficulty in participating in everyday activities to live more productive and enjoyable lives. We can help your child to become more independent in the things they need and want to do, including:

- getting dressed
- cleaning their teeth
- toileting and washing
- play
- school
- leisure activities (sports, games, hobbies, social life).

How do we work?

We work with children aged 0 - 19 years who have difficulty with participating in everyday activities due to a physical disability or medical condition.

Together with parents and other professionals, we help children to achieve their full potential by:

- Assessing your child's strengths and needs.
- Encouraging activities which will develop your child's skills.
- Removing environmental barriers to your child's participation wherever possible.
- Reducing the impact of your child's illness or disability and building on their strengths.
- Signposting you to other agencies who can help.

Who can refer?

We accept referrals from any professional who knows your child including GP, school, SENCO and other health professionals.

2

What we do

We work with children and their families/carers in clinics, home or school as appropriate.

We provide assessment and intervention to develop your child's self care and independence skills, fine motor skills, visual perceptual skills and ability to play and participate in community activities. We achieve this by:

- Offering information and advice about how you can help develop your child's abilities.
- Offering group or individual treatment sessions.
- Providing (or giving advice on) aids and equipment that will help your child with their everyday living skills.

The appointment

An initial assessment and appointment usually lasts approximately one hour. A map of the venue will be sent with your appointment letter.

On your first visit please bring any information e.g. letters or reports you have about help that your child is currently receiving from school or other services, any questionnaires you have been sent to complete and your child's Personal Child Health Record (red book).

We will make every effort to keep our child's appointment time. However, it is very difficult to know in advance exactly how long each appointment or home visit will take as each child's needs are different.

TInterpreters/accessibility

Interpreters (including British Sign Language) are available to attend visits. If you need an interpreter or have any other questions about the service or accessing facilities (such as wheelchair access) please telephone the number on the front of this leaflet before your appointment so that we can arrange this for you.

3

How often to attend?

Following your initial appointment we may provide you with advice or refer you to another service. If regular sessions with an occupational therapist are needed, a therapy plan of the number of sessions required and dates will be agreed between you and your therapist. The venue may be different to that of your first appointment depending on your child's needs. If you are unable to attend please contact us (number on the front of this leaflet) in good time, so that we are able to offer your appointment to someone else.

Quality

All our occupational therapists are registered with the Health Professions Council (HPC) as the national regulatory body and the service has links with the College of Occupational Therapy.

Our therapists maintain (and keep ahead of) local and national initiatives to ensure quality is being achieved with children and families within Leicester, Leicestershire and Rutland. All occupational therapy staff have enhanced Disclosure and Barring Service (DBS) clearance. The DBS replaced the Criminal Records Bureau (CRB).

If you need help to understand this leaflet or would like it in a different language or format such as large print, Braille or audio, please ask a member of staff.

Opening times:

Monday to Thursday
8am - 5pm

Friday 8am - 4.30pm

Date implemented: October 2013
Last reviewed: May 2023
Review date: May 2025
Leaflet No. 262 - Edition 5
Replaced leaflet ct3813/CCHS in October 2013

Appendix 12 - Signing with your child – why using signs can help your child communicate and talk

NHS
Leicestershire Partnership
NHS Trust

Signing with your child

Why using signs can help your child communicate and talk

Information for
parents and carers

Children's Speech and Language Therapy Service
Bridge Park Plaza
Bridge Park Road
Thurmaston
Leicester LE4 8PQ
Telephone: 0116 295 5256
Mon - Thurs: 9am - 5pm
Fri: 9am - 4.30pm

www.leicspart.nhs.uk
Email: lpt.feedback@nhs.net

Signing with your child

Some children need extra help when learning to communicate. Your therapist may recommend using signing when talking to your child.

We often use body language, facial expression and gestures when we talk. These add meaning to what we are saying. Signs are easy to learn as many of them look like these natural gestures. Signs are special movements that we make with our hands. Each sign stands for a word.

Research has shown that signing is helpful. Signing does not stop children from talking, in fact research has shown that children who learnt signs first found it easier to learn words.

Signs can help your child...

- Say more words
- Experience successful communication
- Pay attention and listen when you are talking to them
- Understand what adults are saying by giving them extra clues.

Signs can help you...

- Understand what your child means when they do not have the words to say what they want
- Understand what your child means when their words are unclear.

We use a system of signs rather than children's own gestures. This helps everyone to share and understand the meaning of the signs.

Signs are used in the community. They are widely used in local schools and nurseries.

2

Free one day signing course

We run a free online signing course for parents and carers. This course teaches some useful, everyday signs and shows how to use them with your child.

Ask your child's therapist if you would like more information on signing courses.

Quotes from parents who have been on the course:

3

Useful Websites

- www.makaton.org
- www.bbc.co.uk/tiny-happy-people
- https://singinghands.co.uk/
- https://speechandlanguage.org.uk/
- https://healthforunder5s.co.uk/
- www.leicspart.nhs.uk/service/childrens-speech-and-language-therapy-service/

If you need help to understand this leaflet or would like it in a different language or format such as large print, Braille or audio, please ask a member of staff.

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LPT- Leicestershire partnership NHS trust
UHL- University Hospitals Leicester

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