

Down's Syndrome Pathway

Version 5.0



**Humber and North Yorkshire
Health and Care Partnership**

Developed by
Hull and East Riding of Yorkshire Health and Care Partnerships



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Please note the most up-to-date version of this pathway can be found on the Hull Health and Care Partnership website.

www.hullccg.nhs.uk/downssyndromehull

No one ever tells you just how amazing your child will be when they are born, you are just filled with fear; fear of the unknown, fear for your baby about how will society view my child? You're met with such low expectations, doom and gloom, sombre looks and whispers.

In reality you are parent to a beautiful baby, who just wants to nurture and love them just as any other parent does.

The care pathway, it gives you hope, something we as parents need in those very precious early days.

You need a clear view of what to expect in the future and to know that your beautiful baby will be ok.

So thank you for listening to us (in developing and using the pathway) I don't think you realise just how much this means

Local Parent (Vicky Abbott) of a child with Down's Syndrome

"But the first, most important thing I want you to always remember: everyone with Down Syndrome is a new and different person and it isn't the most important thing about them!"

Elizabeth Elliot, (author who happens to have Down's Syndrome) from her book Can I Tell You about Down Syndrome

Pathway development

This pathway was originally developed in partnership with parents, carers, health professionals and people with Down's Syndrome. This pathway continues to be reviewed and updated by Samantha Findlay, Health Lead at Downright Special in consultation with health services. Further information can be found at www.hullccg.nhs.uk/downssyndromehull. If you would like to be involved in the future development of this pathway, please email sam@downrightspecial.co.uk.

If there are any errors noticed or changes required please email corrections to Hull Health and Care Partnership hnyicb-hull.contactus@nhs.net or sam@downrightspecial.co.uk. If the error presents a significant clinical risk, please contact Hull Health and Care Partnership on Telephone: 01482 344700 or email hnyicb-hull.contactus@nhs.net

Introduction

Please refer to Glossary of terms, if required, at the back of this document

Any person who has Down's Syndrome is a person first. As with any other child or adult, they will have their own unique personality and attributes. It is important to consider the holistic experience of a person's whole life and to value and support the experience of Down's Syndrome as part of that. Down's Syndrome does not define someone.

Down's Syndrome is the commonest autosomal anomaly, present in 1 in 1000 live births. In the majority of cases (95%) there is an extra chromosome, 47 chromosomes rather than 46. 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 chromosome translocation involving chromosome 21. In Hull and East Yorkshire there are approximately five live births per year of babies who are diagnosed with Down's Syndrome.

Some families know that their child is going to be born with Down's Syndrome due to screening processes, while other families have no indication that their child will have Down's Syndrome until they receive a diagnosis after birth. Even though everyone who has Down's Syndrome is different, there are some clinical features present at birth, and some health conditions they may be more prone to.

What is a care pathway?

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

Feedback from families has identified the need for a clinical care pathway and clinical guideline for children with Down's Syndrome. Input has been sought from parent/carers and other services involved. Navigating the complex offer of services is exacerbated due to provision being across health, social care and education. The transition to adult services from children's services is often a time of anxiety for people, however this pathway is designed to make this process clearer and can give people assurance that there are processes in place for both children and adults. This pathway will enable people to navigate their way through health

services to ensure no one who has Down's Syndrome gets 'left behind'. It is effectively putting all the health information pertinent for people with Down's Syndrome in one place. This may be especially helpful at a time when families are also experiencing emotions associated with adjustment to diagnosis. The document is aimed at both families and professionals therefore contains a mix of informal and more technical information.

Multidisciplinary representatives from Community Services, Hull University Teaching Hospitals Trust, education, Humber Teaching NHS Foundation Trust, City Health Care Partnership, other local services, and parents, set up a pathway group to produce a clinical pathway emphasising the need for information and engagement with families. Services for adults who have learning disabilities have also been involved in the development of this pathway, and links to their easy read resources have been used to support the pathway.

This pathway does not replace those services that all children and adults have access to; e.g. GP services, midwifery, health visiting, school nursing, Therapy Services, Community Health Services and hospital services.

It seeks to clarify additional services that may need to be involved in the care of a person with Down's Syndrome because of some common health difficulties experienced by some people who have Down's Syndrome.

These guidelines are largely based on work done by Down's Syndrome Medical Interest Group (DSMIG, UK and Ireland) who have produced guidelines for basic medical surveillance in children with a diagnosis of Down's Syndrome. These guidelines and a wide range of other health information can be found at www.dsmig.org.uk. The Down's Syndrome Association have a lot of useful information relating to health and wellbeing and other important issues for people who have Down's Syndrome, and their families.

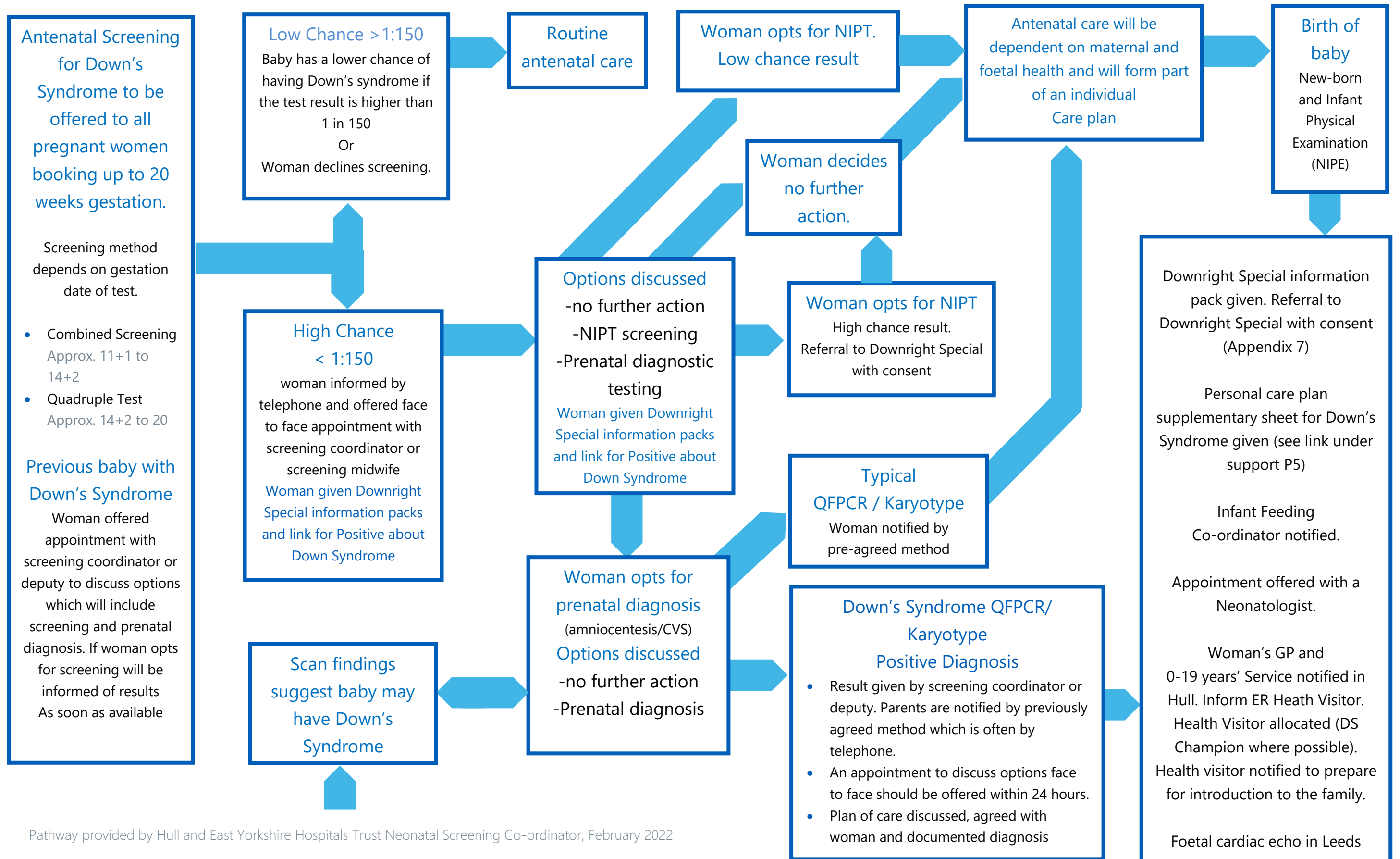
www.downs-syndrome.org.uk

We would also like to acknowledge the work done by Nottingham Down's Syndrome Children's Services team led by Elizabeth Marder and we have utilised their guidelines for this pathway. We have also used the Grampian and Leicestershire Down's Syndrome pathways as reference tools. Further acknowledgements can be found at the back of this Pathway.

The pathway has been co-produced with parents/carers/ service users and professionals to ensure the information is accurate, and is driven by those who will benefit the most from using it.

Consent from parents and carers should be obtained prior to referral and notification of needs within the pathway as per local policy. Clarification regarding consent arrangements for each service should be sought.

Antenatal screening



Useful links and contacts

Information about the tests for Down's Syndrome

- [Screening test for you and your baby](#)
[Public Health England, NHS Screening Programmes]
- [Screening for Down's, Edwards' and Patau's syndromes](#)
[NHS Choices]

Information and contacts for positive diagnosis

<https://www.downs-syndrome.org.uk/about-downs-syndrome/pregnancy-and-baby/looking-forward-to-your-baby-2/>

Support for professionals delivering a positive diagnosis

<https://www.downs-syndrome.org.uk/our-work/services-projects/training/tell-it-right-webinar-for-maternity-services-and-universities/>

Support for parents telling friends and family

<https://www.downs-syndrome.org.uk/wp-content/uploads/2022/12/Friends-and-family-leaflet-web-version-single-page.pdf>

Information and Support for all

[Positive About Down Syndrome – A website by parents for parents and parents-to-be](#)

Antenatal and New-born Screening Co-ordinator

01482 382737

East Riding Early Support Panel

eyst@eastriding.gov.uk

Downright Special (Hull & East Riding Down's Syndrome Support Group)

01482 420160

enquiries@downrightspecial.co.uk

Or register/refer online

<https://www.downrightspecial.co.uk/contact-us>

Antenatal screening guidance

In England all pregnant women under 20 weeks gestation are offered screening for Down's Syndrome at their booking appointment by the community midwife or booking midwife.

The decision whether to accept or decline screening is up to the woman, and enough time should be given to enable them to come to a decision.

If a woman has had a previous baby with Down's Syndrome then the screening coordinator or deputy will discuss options which include screening and prenatal diagnosis. If the current NHS screening pathway is followed then the woman can be informed of her results by telephone as soon as they are available, if she wishes.

Prenatal options

Some women decline screening for Down's Syndrome. If however the woman has accepted screening and gets a higher chance result, non-invasive prenatal testing (NIPT) and prenatal diagnostic testing will be offered. Further information can be found at:

<https://www.gov.uk/government/publications/cvs-and-amniocentesis-diagnostic-tests-description-in-brief/nhs-fetal-anomaly-screening-programme-chorionic-villus-sampling-cvs-and-amniocentesis-information-for-parents>

The decision whether to accept or decline further testing is up to the woman, and enough time should be given to talk through the options and come to a decision. Further information about diagnostic tests can be found on NHS choices website;

[Screening in pregnancy: CVS and amniocentesis information for parents - GOV.UK \(www.gov.uk\)](#)

Communicating diagnosis/results

At the point of prenatal diagnosis, agreement should be made between the woman and the health professional (usually the Screening Coordinator or Deputy) to establish how the results will be communicated. Results will usually be given over the phone with the opportunity to discuss face to face, however the woman will always have a choice as to how she wants to receive results.

Support

If a diagnosis is made antenatally, choices available to a woman and a personalised plan of care will be discussed including the supplementary sheet for Down's syndrome which can be found at : <https://www.humberandnorthyorkshirematernity.org.uk/pregnancy-journey/personal-care-plans-/>

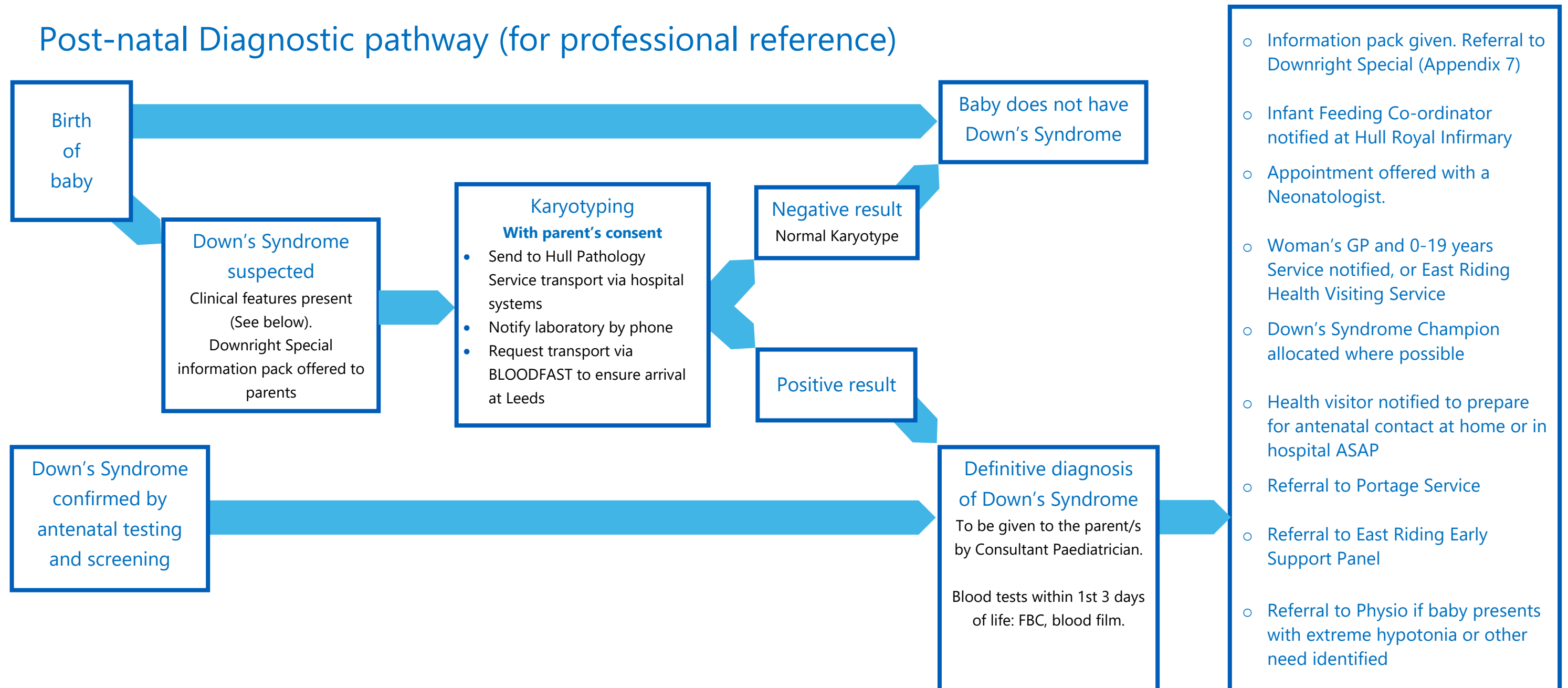
Information about Down's Syndrome including local and national support organisations such as the Down's Syndrome Association, Positive About Down's Syndrome and Downright Special will be offered.

Contact will be made with the 0-19 years Service in Hull or the Early Support Panel / Health Visitor in the East Riding; and the child will be allocated a Health Visitor. Where possible this will be a Down's Syndrome Champion. A referral to Downright Special with consent may also be made.

Counselling

Being told that a baby may have Down's syndrome can be difficult news. Information and time should be offered to allow a woman and her partner to discuss the impact of the diagnosis upon them and their family and obtain the necessary support from services available to them.

Post-natal Diagnostic pathway (for professional reference)



Clinical features at birth some babies may have some of the following

| General | Facial and eyes | Abdomen | Limbs | Heart and blood |
|---|---|--|---|--|
| <ul style="list-style-type: none"> • Poor feeding • Flat occiput (back of head) • Short broad hands • Single transverse palmar crease (crease across palm of hand) • Low muscle tone • Short neck | <ul style="list-style-type: none"> • Prominent epicanthic folds (Skin fold in upper eyelid) • Upward slant of eyes • Brushfield spots in the iris • Low set small ears • Flat nasal bridge • Congenital cataract • Glaucoma • Tongue may protrude from mouth. | <ul style="list-style-type: none"> • Hirschsprung's disease (bowel problem) • Intrahepatic biliary hypoplasia (Liver problem) • Duodenal atresia/stenosis (Intestine problem) | <ul style="list-style-type: none"> • Short incurved little fingers • Sandal gap between first and second toes • Dislocation of knee • Hip problems. | <ul style="list-style-type: none"> • Atrial and ventricular septal defects • Congenital leukaemia – (Commonly AML and acute megakaryoblastic leukaemia) • Mild Pancytopenia (reduction in blood cells) • Neutropenia (low levels of a type of white blood cell) • Transient abnormal myelopoiesis (abnormal number of certain blood cells) • Polycythaemia (increased number of certain cells) |

Useful links and contacts

Health Visiting Teams

Hull 01482 336634 or 01482 344301
East Riding Single Point of Contact 01482 689689

East Riding Early Support Panel

eyst@eastriding.gov.uk

Downright Special

01482 420160
enquiries@downrightspecial.co.uk
Or register/refer online
<https://www.downrightspecial.co.uk/contact-us>

Diagnosis pathway guidance

Chromosomal blood samples should be taken with consent from Parents and sent to Hull Pathology Service to be transported by hospital systems. **It is essential to telephone the laboratory** to inform them of the imminent arrival of the sample and to request transport by 'Bloodfast' and not the shuttle system. This would ensure the sample arrives at Leeds Cytogenic Laboratory the same day, and testing can be started as soon as possible, (preferably that day or the day after). Sending a sample by shuttle can add unnecessary delay. Non urgent samples or a very low likelihood of a positive diagnosis may be sent routinely if clinically appropriate.

Diagnosis and disclosure

Parents should be told of diagnosis as soon as possible, preferably by a senior Paediatrician and the responsible Consultant. Chromosome analysis should be requested urgently, but advice of the likely diagnosis should not be delayed to wait for the results. A Downright Special new parent information pack is available on the ward to give to parent/s which includes advice around adjusting to diagnosis. Contact can be made with Downright Special by family or staff at any time to request emotional or practical support (appendix 7)

Medical history and examination

Routine neonatal examination should pay particular attention to common complications of Down's Syndrome such as bowel atresias, Hirschprung's disease, cardiac defects and cataracts. See appendix 8 for DSMIG schedule of recommended health checks and appendix 2 for recommended ophthalmic screening.

Chromosomes: Ask for a rapid FISH test first and full test as soon as possible. Two millimetres of blood (less may be possible) in a lithium heparin bottle and send to lab straight away or store specimens in fridge if out of hours.

Full blood count (FBC) and blood film to check for a serious blood disorder: Minor abnormalities in a blood count are commonly seen and should be managed as for any other baby. Transient abnormal myelopoiesis (TAM) is reported to occur in 10% of babies with Down's Syndrome and may need advice from the Paediatric Haematologist.

Thyroid screening: Routine New-born screen is satisfactory, but it is necessary to chase and record the result. Record TSH result from new-born blood spot. Thyroid screening will need to take place routinely throughout life.

Clinical cardiac assessment:

This should be performed by a senior paediatric trainee or Consultant prior to the baby leaving the hospital and should include a physical examination. If cardiac murmur is present, then prior to discharge baby must be reviewed by the Neonatal Consultant and an echocardiogram take place before discharge. If a baby is asymptomatic and antenatal scans are normal, then a scan should be arranged within first 8 weeks of life as an outpatient.

Postnatally, all babies should have oxygen saturation monitoring whilst still in hospital on the post-natal ward or Special Care Baby Unit.

If there is no murmur present, antenatal scans were normal, and the oxygen saturations have remained satisfactory, then follow up with the Paediatric Cardiologist can be arranged as an Outpatient.

Note: All babies with a significant left to right shunt should be referred for RSV prophylaxis.

Physio referral: Make referral if baby presents with extreme hypotonia or another need identified (Appendix 5). Baby will usually be seen on discharge.

Universal neonatal hearing screen.

Check this has been done and record the result.

Infant Feeding Coordinators

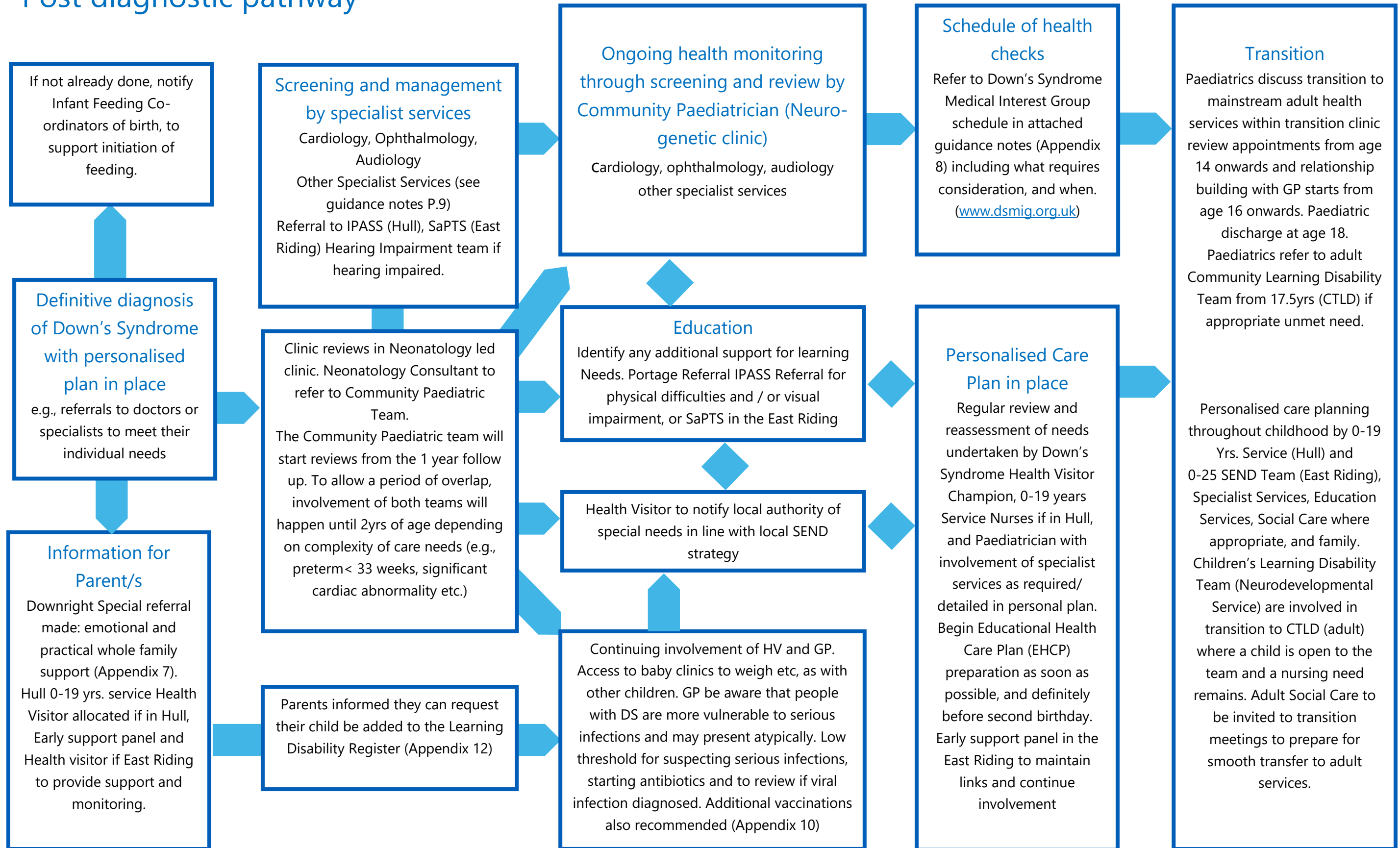
Should be notified of the birth of a baby who has Down's Syndrome regardless of the chosen/preferred method of feeding. This will enable the Co-ordinators to support the parent/s to establish feeding, as we know that babies who have Down's Syndrome can be poor feeders for a variety of reasons including sleepiness, jaw/tongue/ muscle tone/co-ordination issues.

Referrals/notifications to be arranged by neonatal team as part of discharge preparation

The 0-19 Years' Service should be contacted if the child is from Hull, or the health visiting team in the East Riding as soon as it is identified that a baby may have Down's Syndrome. The Children's Community Nursing Team may also be contacted for further support and advice if there is a nursing need present.

A comprehensive medical assessment according to the guidelines must be carried out prior to discharge. A Neonatal discharge letter for babies requiring inpatient treatment will be sent to the GP and named Health Visitor and a clinic appointment arranged in Neonatology. Referral to Portage Service with consent from parents and notification to the local authority SEND Team.

Post diagnostic pathway



Children's growth should be plotted on growth charts (centiles) specific to children with Down's Syndrome. These are to be kept in the personal child health record (Red Book). The pages are green in colour.

Useful links and contacts

NB- Occasionally numbers may change without us knowing – please refer to organisation's website if necessary.

Family and Setting Support Team
(Offering Portage)

Hull 01482 616667/East Riding 01482 392189

Community Paediatric Secretaries
01482 315586

Paediatric Speech and Language Therapy
01482 692929 (option 3)

Children's Occupational Therapy Service
Hull 01482 692929 (option 4)/East Riding 01482 478898

Children's Community Physiotherapy Service
Hull 01482 336774.

Email: hnf-tr.childrenphysio@nhs.net

Hull Royal Infirmary Acute Paediatric Physio Team
Hull 01482 674532

Email: paedphysio.hri@nhs.net

Paediatric Audiology Service
Email: hyp-tr.paediatric.audiology@nhs.net
01482 623072

Children's Community Nursing Team-Continence Service
01482 344075

Hull and East Riding Children's Neurodiversity Service. [Autism/ADHD assessment](#), [LD Team](#), [Sensory Service](#), [SEND Sleep support](#).
01482 692929 (option2).

[Hull and East Riding Children's Neurodiversity Service \(humber.nhs.uk\)](#)

Email: hnf-tr.herneurofrontdoor@nhs.net

See website (link above) for updated information inc. referral forms (including children's learning disability team)

Hull Learning Disability Wellbeing Service
[City Health Care Partnership \(chcpcic.org.uk\)](#)
01482 335642. Service covers Hull however website content accessible to all.

Hull Local Offer Website
<https://hull.mylocaloffer.org/>

East Riding Local Offer Website
<https://eastridinglocaloffer.org.uk/>

Post diagnosis guidance

First Year

The family will receive ongoing support and visits from their named Health Visitor from the 0-19 Years' Service, in Hull and from Health Visiting and Early Support in the East Riding.

The family will receive ongoing care from the Neo-natal team Paediatrician (3 and 6 mth. reviews). Referral is then made to the Community Neurogenetic Clinic for the 1yr review. If Neonatal Team are supporting with ongoing medical needs, there may be a short overlap. Other referrals and introductions will be made by the 0-19/Health Visiting Service/Community Paediatrician/Early Support Panel. This will include Portage and education provision.

Initial visits – Health Visiting Team (0-19 Years Service)

The initial new birth visit will take place as early as possible following discharge home. The purpose of this initial visit is to give the parents written and verbal information about Down's Syndrome, Information about services in Hull and the East Riding of Yorkshire and an opportunity to talk about the diagnosis and to ask questions.

Notification to the LA of the clinics additional needs to be done by Health Visitor Champion / Health Visitor /Early Support Panel. IHV Good Practice Points for Health Visitors about supporting children with DS and their families (including growth, feeding and development) can be found here <https://ihv.org.uk/for-health-visitors/resources-for-members/resource/good-practice-points/generic-gpps/supporting-children-with-downs-syndrome/>

Information to be gathered prior to initial visit: In addition to the usual information, you would need for a first visit, it would be useful to consider the following.

- Confirm that the parents are ready to meet the named Health visitor
- Was the child expected to have Down's Syndrome?
- What do the family already know about Down's Syndrome?
- Is the chromosome result available? If not, when will it be?
- Associated health/feeding difficulties e.g., are they discharged home with tube feeding. (If so, has a competency training pack been completed? Is there adequate supplies and arrangements for consumables)

Information to be given to the family on first visit:

- Downright special new parent pack (if not given in hospital)
- Green Personal Child Health Record (PCHR) inserts, these need to be obtained as soon as possible to ensure child growth is plotted on appropriate charts specific for Down's Syndrome. <https://www.dsmig.org.uk/information-resources/growth-charts/>
- Department of Health early start materials – Down's Syndrome Booklet
- Encourage access to community Child Health clinics for weighing, and advice around development and general child health. Share information about specialist infant feeding support and perinatal mental health service (East Riding).

Follow up visit (within 1st month of life)

This usually takes place at home but may need to be in the hospital if the child is still an inpatient.

General discussion and provision of further information regarding Down's Syndrome and the locally available services (e.g., Downright special)

Appendix 7

Specific Down's Syndrome literature from the Down's Syndrome Association to be given to the family.

Offer the family the opportunity to meet with other families if not already had contact with Downright Special.

Remind families they can request their child be added to the LD Register from birth and discuss benefits of (Appendix 12)

Confirm that the Neonatal team have:

- Arranged the following investigations and completed a discharge letter to the GP and Health Visitor.
- Echocardiogram done or booked through Outpatients with paediatric cardiologist (follow-up arranged if necessary)
- Hearing Screen
- Karyotype and, if parents not aware of result, when and how will this be communicated with them.
- GP informed.

Notes for the Down's Syndrome Champion / 0-19 years' Service/ Health Visitors / School Nurse

Pre-School – At least annual review with the Community Paediatrician Enquire regarding continence (including whether frequency and consistency of stool is abnormal) and any delay with toilet training.

Referral to continence team if appropriate following examination by GP (Appendix 11)

Disability Living Allowance: The family will have a right to apply with support from agencies.

Multi-agency review meeting arranged around 2 ½ -3 years of age if not done before. - Request for Education, Health and Care Plan preparation and assessment to be made. The 0-19 Years' Service to organise this if not already taken place.

Ongoing support from the named Health Visitor/Down's Syndrome Champion continues in addition to universal services that all children receive. Support around education transition (when starting primary and secondary school)

School age

At least annual review by local Community Paediatric Service (Neuro-Genetic Clinic) up to age 18.

EHCP Transition Review in year 9.

Transition to adult services, age 14-18

Annual review by Community Paediatrician includes preparation for adult services (transition clinic) from age 14 onwards. Referral to Community Learning Disability Team (CTLD) just before 18 if a need identified (page 14). The Neurodiversity service (children) involved in transition to CTLD where a child is open to the service and a nursing need remains. Social Care to be involved where appropriate.

Paediatrician review schedule & checklists

| 3 Month Review | 6 Month Review | 1 Year Review | 2 Year Review |
|---|---|--|---|
| Medical review; plot growth onto Down's Syndrome chart | As 3 months including vision check (Appendix 2) | First review in community paediatric neurogenetic clinic; care overlaps with neonatal team as required for 1 year. Review and full examination, including ENT and eyes (Appendix 2). Plot growth on Down's Syndrome specific charts (red book) | Clinical examination as previous review. Particular attention to growth (plot on DS chart, low threshold for investigation of coeliac Disease), Any unusual or recurrent infections. Review development. |
| Feeding and Gastro Oesophageal Reflux (GOR) symptoms | Investigations: Thyroid blood test at 4-6 months (DSMIG schedule Appendix 8) | See DSMIG schedule of investigations (appendix 8): Thyroid bloods, vision, hearing, growth, heart, breathing. | Investigations: See DSMIG schedule of investigations (appendix 8): Thyroid, vision, hearing, growth, heart, breathing, blood. |
| Cardiac assessment, check ECHO reported - refer to Cardiology if necessary | Immunity: Discuss maximising via vaccinations per childhood schedule with additional yearly influenza vaccine (Appendix 10). For household members annual influenza vaccine and COVID | Infection: Discuss unusual/recurrent (Appendix 10). Immunity: Discuss immunisation, recommendations as 6-month review | Immunity: Discuss maximising via vaccinations per childhood schedule with additional single dose of Pneumovax II (at least 2 months after final dose PCV. Pneumovax II should not be repeated within 5 yrs. (Appendix 10). Consider blood tests for immune function at discretion of paediatrician. If on testing pneumococcal antibodies low (despite recent Pneumovax II) or concern regarding immunodeficiency discuss with immunology. Yearly influenza vaccine for child and household members. COVID vaccine for household members when available |
| Hearing (Appendix 1) and vision (Appendix 2) | Check new-born hearing results are known; write letter to Paediatric Audiology Service to ensure full review at 8-9 months | Discuss breathing in sleep, annual oximetry test (Appendix 4) and DSMIG schedule (Appendix 8) or if clinical concern and/or refer to ENT; Ensure hearing assessed at 8-10 months | |
| Frequency of urination, bowel function and stool frequency and consistency | If not referred/seen already, refer to SALT for review at 9 months | Discuss therapies input. Referral to physio if concerns about extreme hypotonia and/or gross motor skill development (Appendix 5). Consider referrals to orthotics for assessment; review development (see red book insert for DS milestones) | Check hips, knees, foot position and spine. If not weight bearing, request hip x-ray and ensure physiotherapy input. |
| Infections (recurrent or unusual), Appendix 10 | Infancy Oximetry test. (Appendix 4) and DSMIG schedule (Appendix 8) | Cervical spine (Atlanto-axial instability) discussion; signpost to the DSA website for information, | Discuss toilet training, flag to Health Visitor for advice. Discuss bowels. If stool frequency or type abnormal refer to Continence service (Appendix 11). Low threshold of investigation for Coeliac Disease. |
| Referral to physio if concerns about extreme hypotonia and/or gross motor skill development (Appendix 5) | Check SEND /Early Years Support Team aware of the child. (Health Visitor to ensure an Early Years Support / SEND team referral has been made to the Local Authority.) | Check hips, knees, foot position. Review spine | Discuss whether any emerging differences in social communication/social interaction (SALT may have noted) compared to other children with Down's Syndrome. Consider possible dual diagnosis of DS/Autism, make family aware of the co-existing diagnoses. |
| Immunity: Discuss maximising via vaccinations per childhood schedule. For household members annual influenza vaccine and COVID vaccine when available | Frequency of urination, bowel function and stool frequency and consistency | Frequency of urination, bowel function and stool frequency/consistency (low threshold for investigation of coeliac disease) | Vision checks. See Appendix 2 guidelines for referral to ophthalmology. |
| Named Health Visitor in place who is, or has access to a Down's Syndrome Champion? | Referral to physio if concerns about extreme hypotonia and/or gross motor skill development (Appendix 5) | Family aware they can apply for Disability Living Allowance. If not refer to Early Help, children's Centres or Downright Special for support. Check Portage arrangements in place | Dental care- referral to specialist dentist indicated? |
| Discuss family life & adjustment to diagnosis. Refer for support if needed. Downright Special/KIDS involved? | | Discuss alert for hospital electronic record | Early education, plans under way? Contact SEND team, named HV or Down's Syndrome Champion if not. |

3 and 4 Year Reviews

Clinical examination as previous reviews. Particular attention to growth (plot on DS chart, low threshold for investigation of coeliac Disease), Any unusual or recurrent infections. Review development.

Musculoskeletal review: Hips, knee position, foot posture, ambulation, scoliosis, perthes, pes planus, arthritis.

Discuss general health. Investigations: See DSMIG schedule of investigations (appendix 8): Thyroid bloods, vision, hearing, growth, heart, breathing.

Discuss breathing in sleep, annual oximetry test (Appendix 4 and DSMIG schedule Appendix 8) or if clinical concern and/or refer to ENT if symptomatic.

Vision checks including squint. Check referral/attendance at eye clinic. Appendix 2 guidelines for referral to ophthalmology

Discuss toilet training, flag to Health Visitor for advice (3 yrs.). If not achieved (age 4 +) refer to continence service for advice/support/ product. Discuss bowels. If stool frequency/type abnormal refer to Continence service. Low threshold for investigation of Coeliac Disease

Immunity: Discuss maximising via vaccinations per childhood schedule with additional single dose of Pneumovax II (at least 2 months after final dose PCV. Pneumovax II should not be repeated within 5 yrs. (Appendix 10). Consider blood tests for immune function at discretion of paediatrician. If on testing pneumococcal antibodies low (despite recent Pneumovax II) or concern regarding immunodeficiency discuss with immunology. Yearly influenza vaccine for child and household members. COVID vaccine for household members when available

Dental care discussion

Discuss Strengths, skills, progress. If concern about any behaviours, sensory processing, sleep refer to Neurodiversity service (Children's LD Team) for an assessment of need.

Discuss any emerging differences in social communication or social interaction (compared to peers with DS). Consider possible dual diagnosis of DS/Autism, make family aware of co-existing diagnoses.

Ask whether child has an ED alert on HUTH EPR. Ask whether child has a health passport document in case of emergency. Refer to Downright Special for support with health passport.

4yr review-Is there continued involvement with the 0-19 Years Service for school transition? If not, contact Health Visitor/School Nurse. Remind family Downright Special can advise/support child in school.

5 Year Review & Annual Review

As for other reviews, repeat full clinical examination. Ensure DSMIG (appendix 8) investigations are continuing as per schedule.

Discuss unusual or recurrent infections.

Immunity: As 3 yr. check (Appendix 10)

Discuss breathing in sleep, oximetry test if not had already by age 5 (Appendix 4 and DSMIG schedule Appendix 8) or if clinical concern above age 5 and/or refer to ENT if symptomatic.

Discuss bowels (low threshold for investigation of coeliac). If stool frequency or type abnormal refer to continence service. Discuss toilet training. If not achieved refer to continence service for continence support and product (appendix 11)

Discuss therapy and educational input. Consider referral to orthotics for assessment or to physio via MSK pathway (Appendix 5)

Vision checks including squint. See Appendix 2 guidelines for referral to ophthalmology

Dental care discussion

Discuss Strengths, skills, developmental progress. Any differences in social communication or social interaction (compared to peers with DS Consider possible dual diagnosis of DS/Autism). If concern about behaviours, sensory processing differences, sleep refer to Neurodiversity service (Children's LD Team) for a holistic assessment of need

Discussion about puberty and sex/relationship education when time appropriate. If extra support required, consider referral to Neurodiversity Service (Children's LD Team) for a holistic assessment of need.

Family aware they can apply for Disability Living Allowance if not refer to Early Help, Children's Centres or Downright Special for advice on applying

Does child have an Emergency Dept alert on HUTH EPR. Does child have a health passport in case of emergency/admission. Refer to Downright Special for support with this. Is child on GP LD Register? (Appendix 12)

Transition to adulthood reviews (14-18)

Transition to relevant (need dependent) adult secondary care specialisms discussed at annual paediatric reviews between ages 14-18. If specialist adult secondary services may be needed (rather than GP care) case discussion at hospital neuro transition MDT. Relationship building with GP from age 16 onwards. Prompt families regarding GP Annual health check (from age 14, appendix 12). If need identified, consider referral to Adult Community Team Learning Disability (CTLTD) from age 17.5 as part of transition planning. CTLTD work alongside paediatrics. Page 14 for full range of support provided by CTLTD. Discharge from paediatrics at 18

Repeat full clinical examination.

Discuss bowels. If stool frequency or type abnormal refer to continence service. Discuss toilet training. If not achieved refer to continence service for continence support and product. Review and transition to adult bowel and bladder service at age 18 (appendix 11). Low threshold of investigation of Coeliac Disease.

Dental care- referral to specialist dental team indicated?

Immunity: Discuss annual influenza vaccine and COVID vaccine when available for YP and household members.

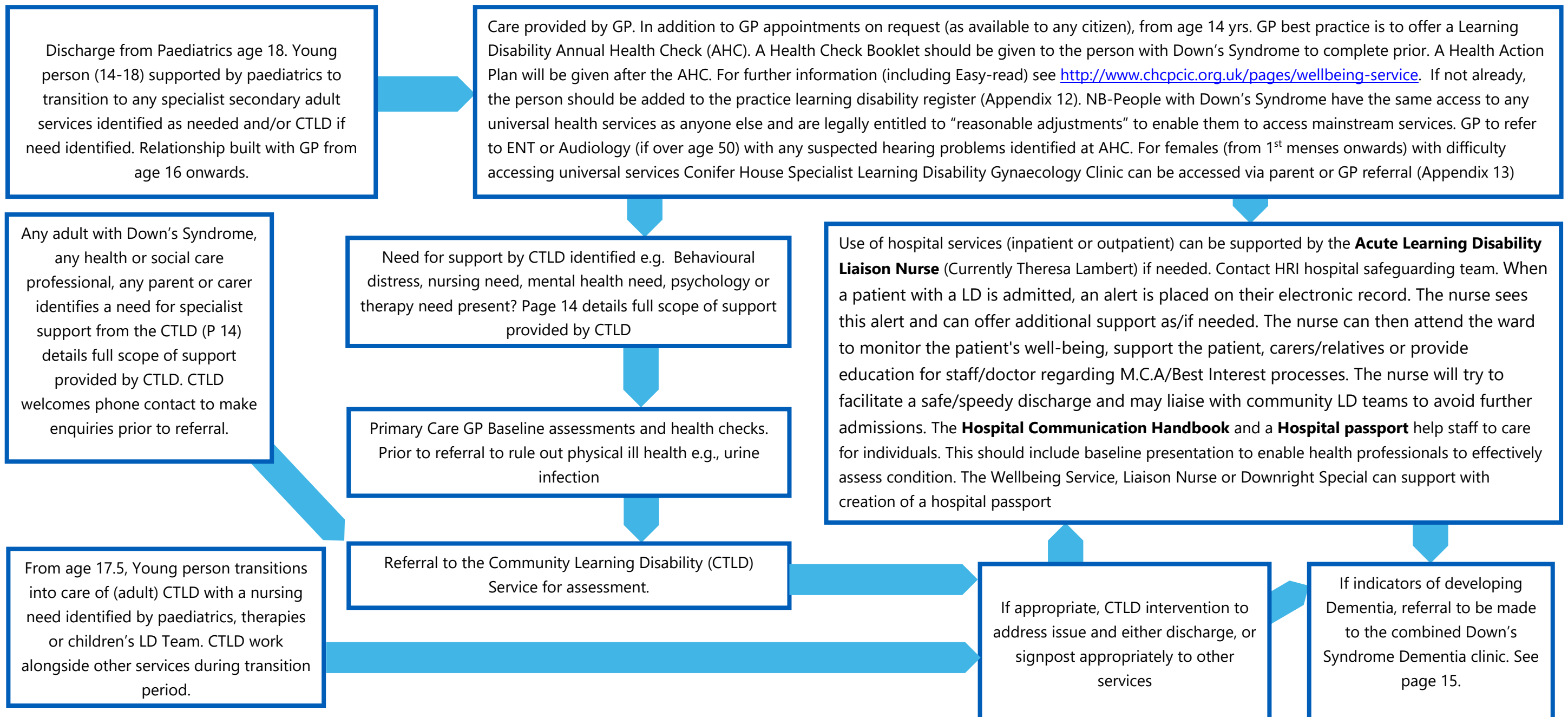
Discussion about puberty and sex/relationship education when time appropriate. If extra support required, consider Referral to Neurodiversity Service (LD Team) for a holistic assessment of need

Males: Discuss that advisable to regularly check the testes. If YP not able to do this himself then it can be included as part of the annual health check with GP." Refer to McMillan Easy-read guide to self-checking.

Discuss Strengths, skills, aspirations, developmental progress. (To age 17.5) If concern about any behaviours, sensory processing differences, sleep refer to Neurodiversity service (Children's LD Team) for a holistic assessment of need. The children's LD Team involved in transition to CTLTD (adults) where a child is open to the team and a nursing need remains.

Does young person have an Emergency Dept. alert on HUTH EPR. Does young person have a health passport in case of emergency/admission. Refer to Downright Special for support with this. Is young person on GP LD Register and receiving an LD Annual Health Check with GP (14 yrs. +) (Appendix 12)

Care Pathway for adults with Down's Syndrome



More information about healthcare for people with learning disabilities on the following website. <http://www.chcpcic.org.uk/pages/wellbeing-service>

Personalisation of care, individual method of communication, access, and capacity to consent to treatment, must all be considered on an individual basis.

Useful links and contacts

Adult Community Learning Disability Team (CTLD)

Hull 01482 336740

East Riding 01377208800

Wellbeing Service

[City Health Care Partnership \(chcpcic.org.uk\)](http://chcpcic.org.uk)

01482 335642. Service covers Hull however website content accessible to all. Information about Annual Health Checks and Health Action plans including accessible information.

Acute Learning Disability Liaison Nurse

Hull Royal Infirmary. The Liaison Nurse sits within the hospital

safeguarding team. Phone the main switch board (01482 875875)

And Request to be connected.

Hull Safeguarding Teams

Children 01482 616092

Adults 01482 616092

East Riding Safeguarding Teams

Children 01482 395500

Adults 01482 396940

Please Note

A person with Down's Syndrome can develop any medical condition as with the general population. The conditions (right) are highlighted as we know there is a higher incidence of those occurring in people who have Down's Syndrome. From age 14 everyone with Down's Syndrome should be able to access an Annual Health Check (AHC) with their GP/primary care team. This is in addition to the universal, needs led access to the GP available to all adults and ensures that physical and mental health needs are pro-actively and regularly reviewed. Between health checks if there are concerns regarding any other health needs, conducting a GP consultation is essential.

Health needs for adults with Down's Syndrome

The following conditions are more prevalent in adults who have Down's Syndrome, therefore screening and a **lower threshold for further investigation** is important. Annual Health Checks should be comprehensive and include assessment and discussion about the following in particular. A Health Action plan to be created/provided following health check. The Down Syndrome Medical Interest Group (DSMIG) exists to help clinicians in their medical management of people with Down Syndrome. [DSMIG – Down Syndrome Medical Interest Group](#)

- Obesity
- Hearing impairment
- Gastro-oesophageal reflux
- Eye problems
- Osteoporosis
- Lower immunity hence more infections
- Diabetes Mellitus
- Dementia and Alzheimer's Disease
- Hypothyroidism
- Constipation
- Hypermobility and joint problems
- Teeth/Dental problems
- Coeliac
- Spinal problems
- Cardiac difficulties
- Epilepsy

- Thyroid Function Test
- Cardiovascular examination
- Sleep discussion, including somnolence. Possible sleep apnoea assessment if indicated.
- Throat and neck examination
- Vision and hearing check (or confirmation these are being checked)
- Immunisations – including Influenza and Pneumococcal Vaccination
- Communication needs
- Medication review
- Lifestyle factors such as smoking, alcohol consumption, nutrition and exercise
- Sexual health (Appendix 13)
- Foot care
- Continence
- Weight, height, blood pressure and heart rate
- Mental health and emotional wellbeing, including mood and anxiety
- Well woman awareness: cervical and breast care screening (Appendix 13)
Well man awareness (testicular and prostate health)
- Consideration should also be given to the carer's health and wellbeing.

Be aware that signs of infection present differently in people with Down's Syndrome. Appendices 9 and 10 contain supporting Sepsis and infection information. The Sepsis Trust offer an online training package [Sepsis for Learning Disability Care Workers | The UK Sepsis Trust](#)

What the Community Team for Learning Disability (CTLD), adults can offer.

The community learning disability team work systematically as a multi-disciplinary team. We work with clients, carers and family in different environments including the family home, day service, supported living and residential settings. The health professionals in the team offer training to internal and external sources to support care of clients.

Psychology

- Talking therapies e.g. loss, negative experiences
- Anxiety management
- Anger management
- Mood problems
- Psychometric testing
- Positive behavioural support plan
- Psycho education
- Relationships
- Supervision and consultation
- Assessment and formulation
- Reminiscence work i.e., memory books, life story work (completed by carers and families following signposting to resources and tools)

Occupational Therapy

- Moving and handling assessment
- Postural management
- Specialist seating
- Developing independence
- Sensory profile
- Environment adaptations
- Equipment provision
- Volunteering or employment
- Personal care
- Daily living skills assessment
- Positive behavioural support plan
- Visual supports e.g., daily routine, activity plans
- Meaningful occupation
- Budgeting
- Travel practice
- Behavioural interventions e.g., mindfulness, sensory strategies, anger management
- Assessment and interventions relating to leisure, social activities and education

Psychiatrist

- Medication management

Speech and Language Therapy

- Dysphagia assessment
- Dysphagia intervention
- Communication assessment
- Visual supports e.g., visual timetables, conversation books, visual aids
- Communication passports
- Communication and behaviour work
- Intensive interaction
- Reminiscence work i.e., memory books, life story work (completed by carers and families following signposting to resources and tools)
- Carer support and advice
- Communication friendly environments
- Staff training
- Advance care planning
- Positive behavioural support plan
- Family/systemic Therapy

Physiotherapy

- Mobility assessment
- Postural management
- Transfers
- Seating
- Exercise advice
- Tone management
- Abdominal massage for chronic constipation
- Falls assessments.
- Chest care at end of life
- Positive behavioural support plan

Epilepsy

- If seizures are suspected we provide assessment, diagnosis and treatment of epilepsy from specialist nurses and consultant neurologist.
- Each individual will have individualised epilepsy management plans which if required will include rescue medication.

- We look at medication management and optimisation providing ongoing support and advice for carers and families as appropriate to the individual.
- Epilepsy awareness and administration of rescue medication training is available for carers if required.
- We also work closely with our colleagues in palliative care to manage the individual's epilepsy at the end of life as there can be complex adjustments required to medications.

Nursing

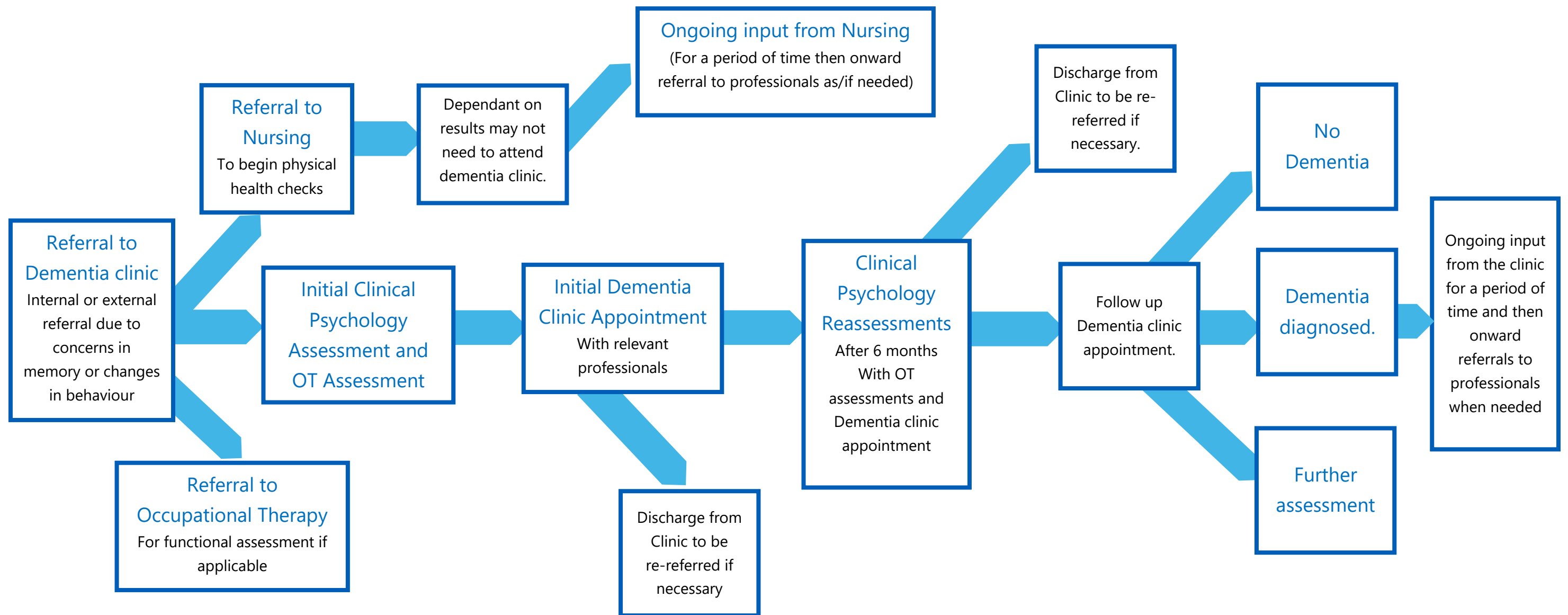
- Health screening: routine and as part of the national screening programs
- Health Facilitation: health action planning
- In depth nursing assessments: to consider holistic needs and strengths.
- Health promotion of any relevant health issues, inclusive of addressing health inequalities and making reasonable adjustments
- Total bowel management assessments
- Functional analysis of behaviour
- Positive behavioural support plan
- Relationship guidance
- Anger management
- Training for families, carers, providers and individuals re: health related topics
- Advocating for individuals
- Joint working with other health, education and social care as part of young person's education and health care plan when in transition
- Medication optimisation
- Desensitisation in relation to treatments: dental, hospital, bloods and any health investigations.
- Interagency working within acute and primary care
- Social inclusion opportunities: friendship groups, RED disco, etc.
- Developing independence
- Continuing health care applications
- End of life support

IST

- The learning disability intensive support team is a multidisciplinary team comprised of Occupational Therapists, Speech and Language Therapist, Nursing, Psychologist and Healthcare assistants. They typically work with complex clients who range of interventions aimed at supporting people in the community.

Hull & East Riding Down's Syndrome and Dementia Clinic

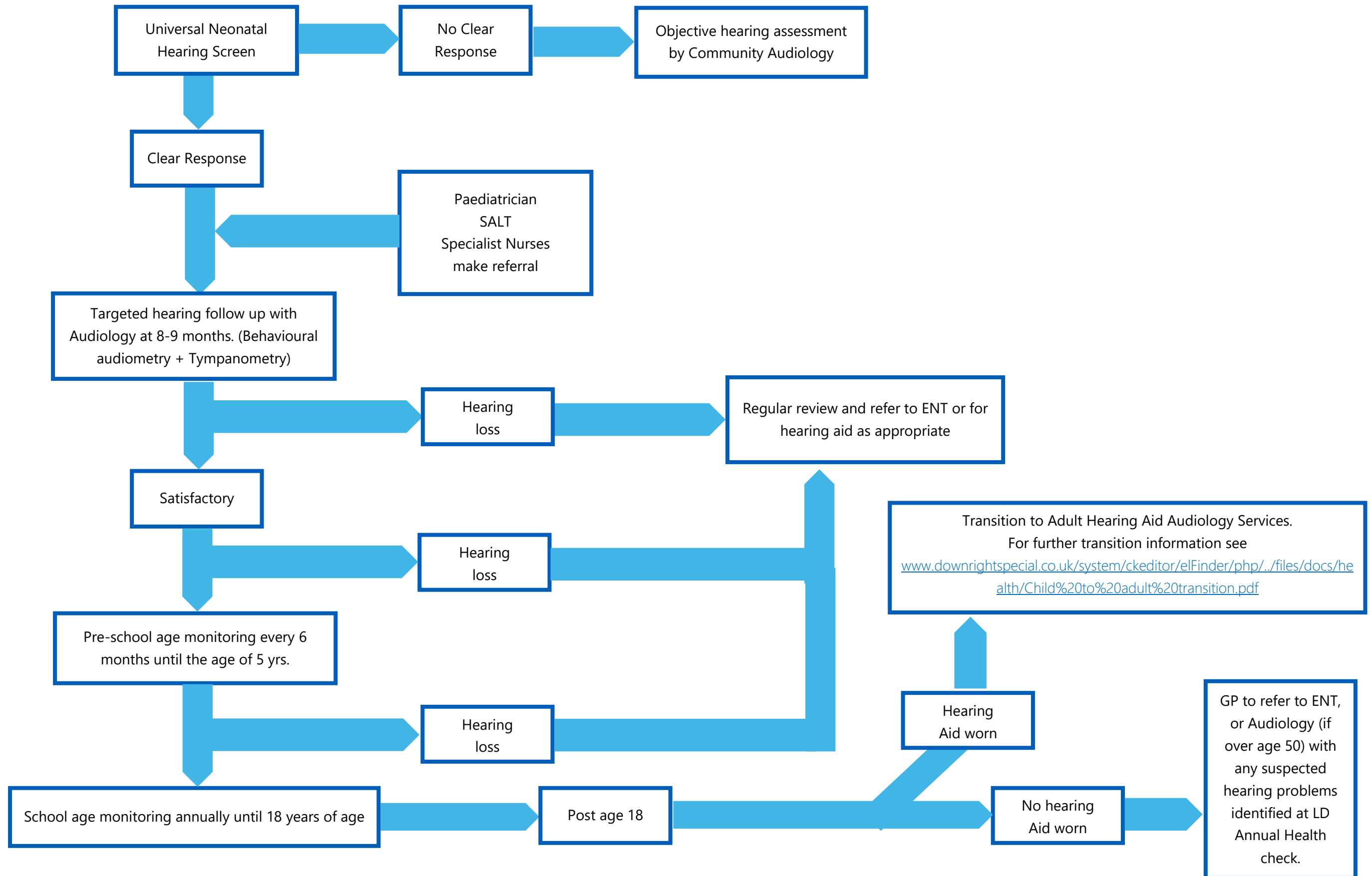
Multidisciplinary pathway for pro-active identification diagnosis and management of dementia for people with Down's syndrome



Prevalence rates increase to 30 – 75% in people aged 60 – 69 with Down's Syndrome (BPS 2015)

British Psychological Society (BPS) and Royal College of Psychiatrists 2015 Dementia and people with intellectual disabilities: Guidance on the assessment diagnosis, interventions and support of people with intellectual disabilities who develop dementia BPS Leicester

Appendix 1 – Children with Down's Syndrome. Hearing Care Pathway.



Appendix 2 Guidelines for referral to Ophthalmology service

Children with Down's Syndrome are very likely to develop vision problems of one sort or another throughout life, so it is especially important that the visual behaviour of children is checked regularly. Look for signs of squint, nystagmus, change in visual behaviour with time and any other parental concern.

If in doubt - refer to Ophthalmology.

The recommended structure devised by Down's Syndrome Medical Interest Group (Down's Syndrome MIG) 2000 for ophthalmic screening is as follows.

Birth to 6 weeks

- Check visual behaviour.
- Check red reflex for congenital cataract and other congenital abnormality such as coloboma of the iris
- Refer urgently to ophthalmology if problem identified/suspected at this stage

3-month review

- Check visual behaviour and red reflex as above.
- Refer to ophthalmology if any concerns are raised

6-month review

- Check visual behaviour and red reflex as above.
- Look for presence of nystagmus either on fixation of target or when following
- Look for presence of squint.
- Ask about any parental concerns regarding visual behaviour.
- Refer to ophthalmology if any concerns.

1 year review

- Check as above.
- Problems with naso lacrimal duct may be a problem so consider referral for this if parents are concerned.

- At age 18 months an alert on system 1 to alert Health Visitors of need to refer to Orthoptic Screening for routine review. Attendance at a local screening clinic will be followed by a referral to an ophthalmologist regardless of outcome.

2-year review

- Check that referral to Orthoptic/Ophthalmic screening has taken place. If not it is recommended that at this stage all children should be reviewed by an ophthalmologist for a fundus and refraction check. This assessment will also include an orthoptic assessment to check vision levels and presence of squint.
- Paediatricians and GPs can refer directly to ophthalmology.
- Health Visitors can refer to orthoptic screening following which the child will be referred on to ophthalmology

3- and 4-year review

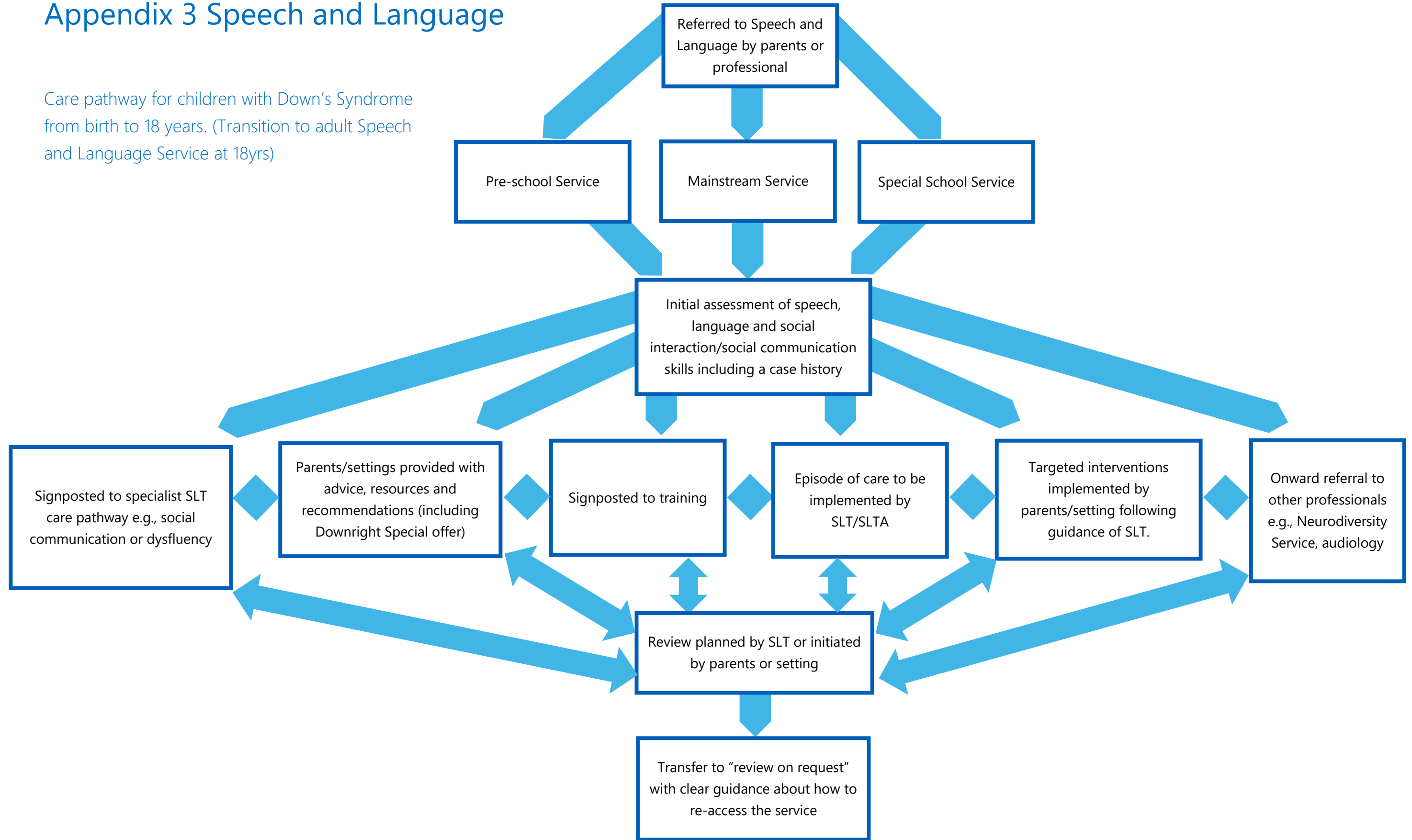
- Checks as above including squint.
- Check that referral and attendance at the eye clinic has taken place.
- If unclear then refer to ophthalmology.

Ongoing

- Repeat vision test at least annually.

Appendix 3 Speech and Language

Care pathway for children with Down's Syndrome from birth to 18 years. (Transition to adult Speech and Language Service at 18yrs)



Appendix 4

Sleep-related upper airway obstruction (SRUAO) or Sleep related breathing disorder (SRBD)

The RCPCH Working Party on Sleep Physiology and Respiratory Control Disorders in childhood reported that:

- Children with Down's Syndrome are at high risk of SRBD and nocturnal hypoxaemia, and the high incidence of congenital heart disease in these children makes the development of pulmonary hypertension a significant risk.
- SRBD may be difficult to identify on symptoms in this group.
- Adenotonsillectomy may have a lower rate of success, but is still indicated.
- Other interventions including CPAP are effective but may be difficult to institute.

They recommended the following:

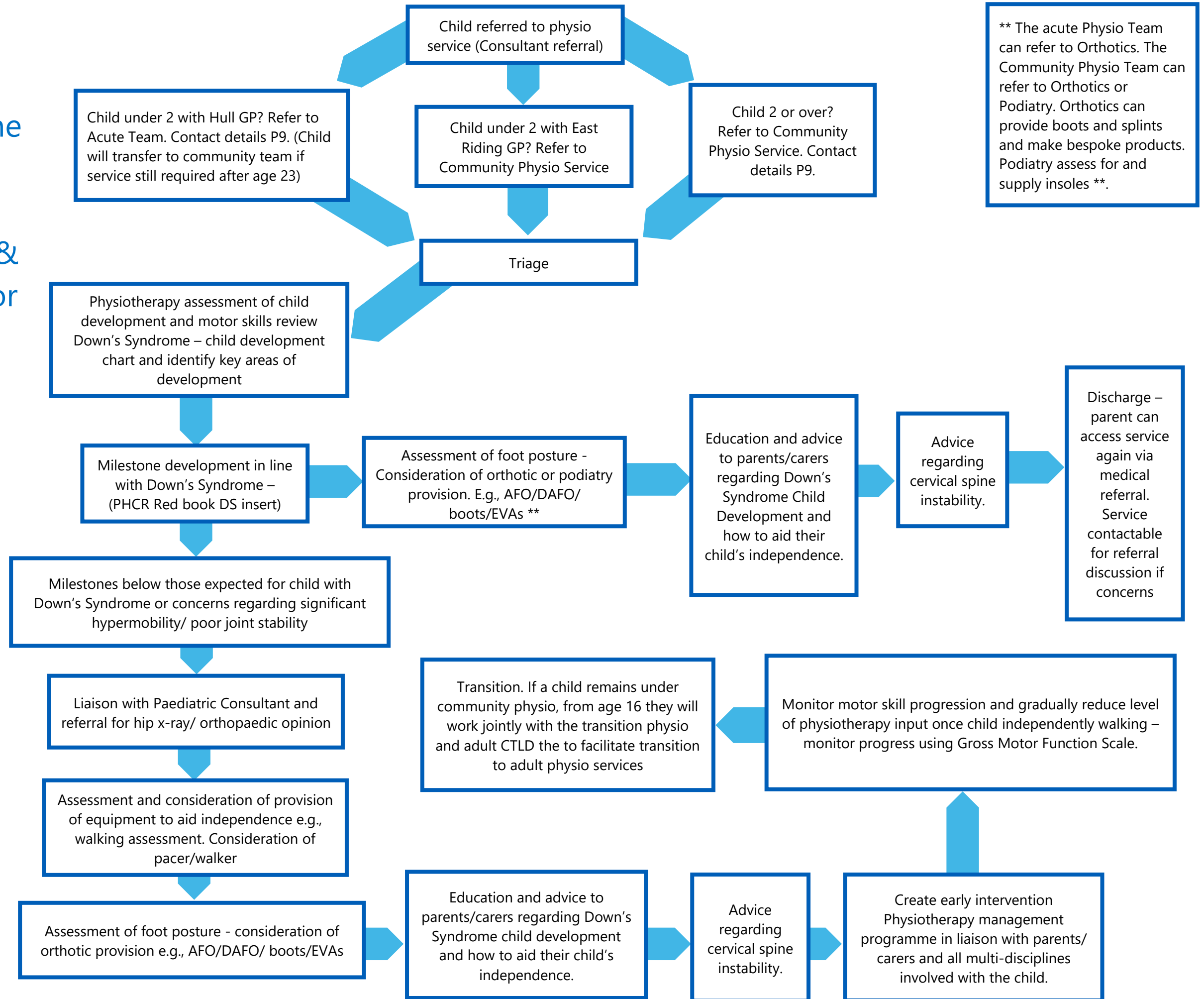
- All children with Down's Syndrome should be offered screening for SRBD, using at least oximetry; suggested screening ages are at least once in infancy then annually until age 3-5 years.
- Children with Down's Syndrome with abnormalities on screening for SRBD, or where there is a clinical suspicion of a false negative screening test, should have polysomnography, including oximetry, airflow, effort and CO₂ measurement. Video should be included if possible.
- If significant SRBD with hypoxia is present in children with Down's Syndrome, then appropriate treatment should be offered.
- Further research is needed on the benefits and risks of screening for SRBD and Down's Syndrome.
- It is acknowledged in the report that "there is no evidence about how long screening should continue in these children". We have arbitrarily taken 3-5 years as including the period of highest risk of OSA. If screening tests are negative up to this age it would seem reasonable not to undertake further tests subsequently unless there are suggestive symptoms.

Symptoms to consider include:

- Snoring
- Sleep disturbance
- Mouth breathing and halitosis.
- Restless sleep
- Chronic rhinorrhoea
- Subcostal and sternal recession
- Odd sleep positions, such as hanging over the bed or sleeping upright with head extended to optimise the upper airway
- Swallowing difficulties
- Recurrent upper respiratory tract infections
- Nausea and vomiting
- Daytime sleepiness
- Persistent or secondary enuresis
- Nocturnal sweating
- Cyanosis
- Apnoea

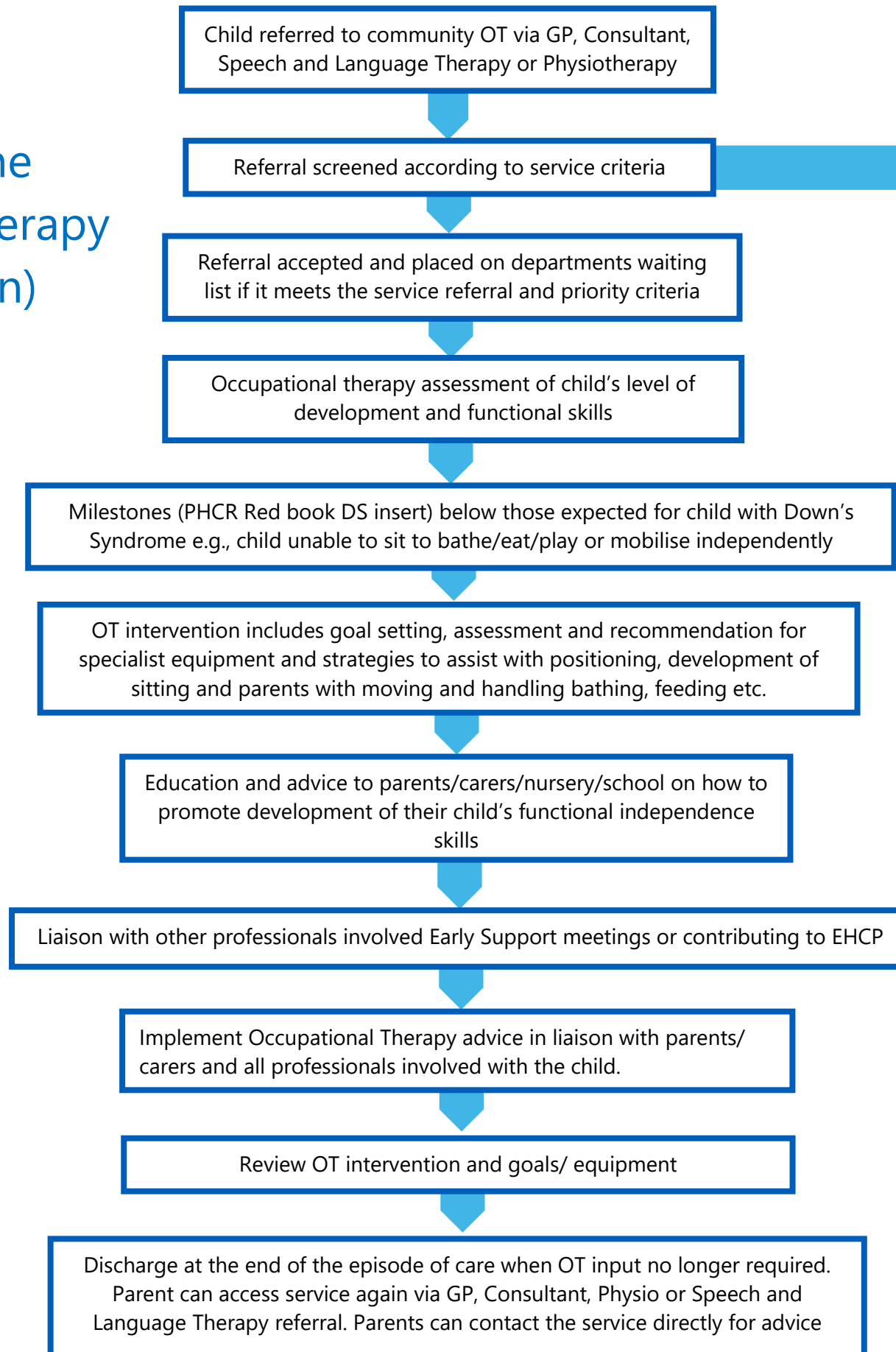
Appendix 5

Down's Syndrome Physiotherapy Pathway For Community & Acute Services for Children



Appendix 6

Down's Syndrome Occupational Therapy Pathway (children)



Referral not accepted as fails to meet criteria (e.g., child meeting expected DS milestones, functional difficulties rather than physical). Referrer informed or signposted to another service e.g., Wheelchair Services **, Local Authority OT.

All referrals received are carefully considered. Advice and signposting to other services or to useful resources will be made. OT Service advises parents to always ask Consultant/GP/Physio/SLT to refer if they think OT could benefit their child.

Large size buggies and wheelchairs are provided by Wheelchair Services. Referral to Wheelchair Services is via OT/Physio (if under their care) or by GP otherwise

Appendix 7 - Downright Special Service Provision

Downright Special is a charity which provides support to families with children with Down's Syndrome in Hull and East Yorkshire as follows:

Antenatal support

- Our information packs are stocked in the Antenatal Clinic at Hull Royal Infirmary, Women and Children's Hospital, for distribution to families with an antenatal diagnosis of Down's Syndrome, or those with a high probability of diagnosis. Packs can also be downloaded from our website.
- Our volunteers are available to talk to families in such a situation, if required.

Neonatal support

- We have been involved in providing training to midwives, neonatal nurses and Paediatricians regarding early support and communication of diagnosis.
- Our new baby information packs are available to all families with new babies who happen to have Down's Syndrome. These include leaflets regarding Downright Special and information provided by the national Down's Syndrome Association.
- When and if families wish, our volunteers can make contact to provide information and peer support.

Health

- Our Health Lead is able to offer 1:1 evidence-based advice and support with health-related matters by phone, online or face to face at group sessions
- Families of children with specific health needs can be put in touch with other families with similar experiences
- A directory of Down Syndrome specific health, education and social service provision is provided to parents of children 0-18 months. A link to the directory can be found on our website
- We work with parents to create a bespoke Hospital Passport document for their child to aid communication in times of emergency
- We have a template letter to assist families requesting their child be added to the Learning Disability Register
- We provide information and signposting to support young people to access GP Annual Health check from age 13.5 yrs.
- With parental consent we can facilitate adding an alert highlighting a child has Down's Syndrome on Hull Royal Infirmary children's Emergency Department's electronic system
- We deliver training sessions for parents and professionals alongside members of the speech and language therapy team, who also visit our educational sessions to enable sharing of best practice.
- Health Visitors visit Downright Special to give further input around health, development and growth.

Early Years Support

- Our Downright Special Friday sessions are for children from birth to 5 years old and offer a chance for parents to meet and to enjoy their babies in a relaxed environment.

- Through our baby group we provide an introduction to signing, speech sound production, communication skills and sensory stimulation.

Education

- Our specialist teachers provide support to children, teachers and teaching assistants in both the pre-school and school settings. This includes advising on annual reviews, special educational provision and target-setting for Individual Education Plans (IEPs).
- Schools are provided with an education pack which includes valuable resources used to support the specific learning profiles of children with Down's Syndrome.
- We deliver training to teachers and teaching assistants regarding specific techniques used in teaching children with Down's Syndrome.
- Each Friday our specialist teachers deliver targeted small group lessons within our group session. These have the added bonus of providing on-going training and support to parents and teaching assistants.

Social

- We host regular social activities for the whole family to allow children with Down's Syndrome, siblings and parents an opportunity to interact in a relaxed environment.
- Our Friday group session includes both structured and unstructured time for children to develop their social and play skills and for parents to meet other parents.

Information

- Our website provides information regarding a number of issues important to families with children with Down's Syndrome.
- We have an active Facebook group for parents as well as a Facebook page, Instagram and Twitter account which provide information to the wider public.
- We have books and resources available to borrow through our online library
- We provide advice, advocacy and support to families in person, over the telephone, by email or social media.

Referral Pathways to Downright Special

- Families can register with us, either via telephone (01482 420160), email (enquiries@downrightspecial.co.uk) or via website <https://www.downrightspecial.co.uk/contact-us>
- Those with an antenatal diagnosis can be referred by the antenatal clinic.
- Referrals are made with permission from the family by any health or education professional by phone, e-mail or online using the referral form <https://www.downrightspecial.co.uk/contact-us>

Appendix 8

* Local Children's audiology exceeds recommended schedule below (see Appendix 1)

DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

| | Birth - 6 weeks | Special checks under 2 years | Preschool checks | School age |
|---------------------|---|---|--|--|
| Thyroid blood tests | Newborn routine heel prick - blood spot test | Age 4-6 months and then every year from the age of 1 year or more often if clinically indicated: Venous thyroid blood test including thyroid antibodies <u>or</u> Fingerprick TSH test | | |
| Eye checks | Newborn routine check including congenital cataract check | Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or short sight | Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity | Repeat vision test every 2 years , or more frequently if recommended by optometrist or ophthalmologist or if concerns |
| | Visual behaviour to be monitored at every review particularly in first year | | | |
| Hearing checks | Universal newborn hearing screen | Full audiological review by 10 months including hearing test impedance check | Annual audiological review or more frequently and if indicated 2 yearly audiological review or more frequently if recommended | |
| Growth monitoring | Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts | | Height and weight should be checked and plotted on Down syndrome growth charts at least annually (BMI checked if concern regarding overweight) | |
| Heart checks | By age 6 weeks , formal heart assessment including Echocardiogram | At all ages low threshold for reviewing heart status if signs or symptoms develop | | From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease |
| Breathing checks | Enquire at every review for uneven breathing during sleep and poor quality sleep. Screen with an overnight pulse oximetry once in infancy and yearly until the age of 5, or at any age if there are symptoms or concerns. Low threshold for detailed sleep studies if symptoms persist, despite normal tests | | | |
| Blood checks | Within the first three days of life, full blood count and blood film to check for a serious blood disorder | If blood film is abnormal treatment or monitoring may be required | | |

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk

Appendix 9 – Makaton resources to support Sepsis management.



Sepsis information

An infection can become sepsis.

Sepsis is dangerous.

You feel poorly.

You may think that you have flu.

If you:

are confused/

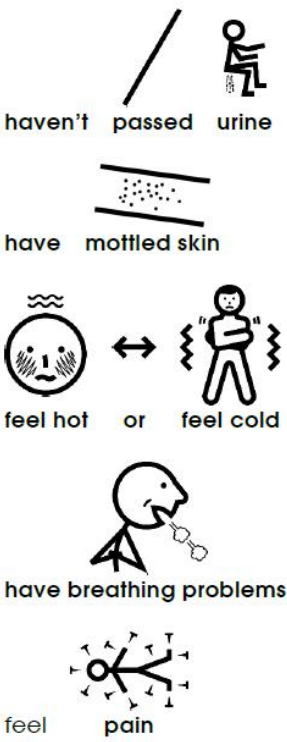


sleepy

Let's talk Makaton makaton.org

For further information on Sepsis, visit the NHS website.



© The Makaton Charity 2019



haven't passed urine

have mottled skin

feel hot or feel cold

have breathing problems

feel pain




You need to go to the hospital, immediately.

For more information look at the

Sepsis Aware Bears Facebook.

Let's talk Makaton makaton.org

For further information on Sepsis, visit the NHS website.



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Appendix 10 – Infection alert and tips for triaging and treating kids with Down's Syndrome

Taken from the Down's Syndrome PCHR (Red book) Page 16.

[A5-Downs-charts.pdf \(healthforallchildren.com\)](https://www.healthforallchildren.com/A5-Downs-charts.pdf)

Most kids with Down's Syndrome (trisomy 21) have some physiological and behavioural differences that make it difficult to assess how sick they actually are.

1. Poor temp control:
may not develop a fever at all, or may be hypothermic instead

2. Weak immune system:
Infections that usually cause only minor illnesses can be dangerous to kids with DS. Amy (in the photo below) spent a week ventilated in PICU when she had chicken pox!

3. Mottle easily:
Kids with DS have poor control of SVR, and get mottled ("corn beefy") with temperature change as well as sepsis, making assessment tricky.

4. Co-morbidities common
Remember cardiac problems, GORD, coeliac and autism (& don't forget the drug history)

5. Leukaemia is more common
and may present atypically

featuring Amy!

Top tips for triaging & treating kids with Down's Syndrome

6. Ask what's normal for this individual child
Assessing levels of alertness, responsiveness, tone etc. can all be difficult if you don't know the individual child at baseline. Ask parents: they know their child best!

7. Narrow tubes, thicker mucus
Kids with DS get more chest & ear infections, and generally produce more snot!

8. Explain and reassure
Kids with DS often have sensory processing difficulties and can be very wary of new sensations: BP cuffs and sats probes may be terrifying. Take time to explain and reassure.

9. Beware of atypical presentations of serious illness
Sepsis can present atypically (as well as leukaemia, see #5) - e.g. chest infections/pneumonia with sepsis presenting as D&V

10. Optimise communication strategies
Speech & language development lags behind understanding, so kids with DS often understand more than they can express. They're often great visual learners (but have poor short-term auditory memory and fluctuating hearing loss) so use sign, pictures and gestures. Speak slowly, clearly and maintain eye contact. Allow for sensory processing delay of several seconds: don't hurry a reply

Keep calm! Just don't forget the extra chromosome

© Elizabeth Herrievan - @LizJ178 (EM consultant & mum of Amy) & Linda Dykes - @mmbangor (EM Consultant & GP)

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DOWN SYNDROME

INFECTION ALERT

This page has been included to highlight to health professionals and parents/carers that children who have Down syndrome may respond differently to infections and need special consideration.

If you are worried that your child may have a serious infection please seek medical advice and show this page.

Children who have Down syndrome are more vulnerable to serious infections and may present atypically. They may not 'appear' to be unwell, so checking with their parents/carers about what is usual for them is important.

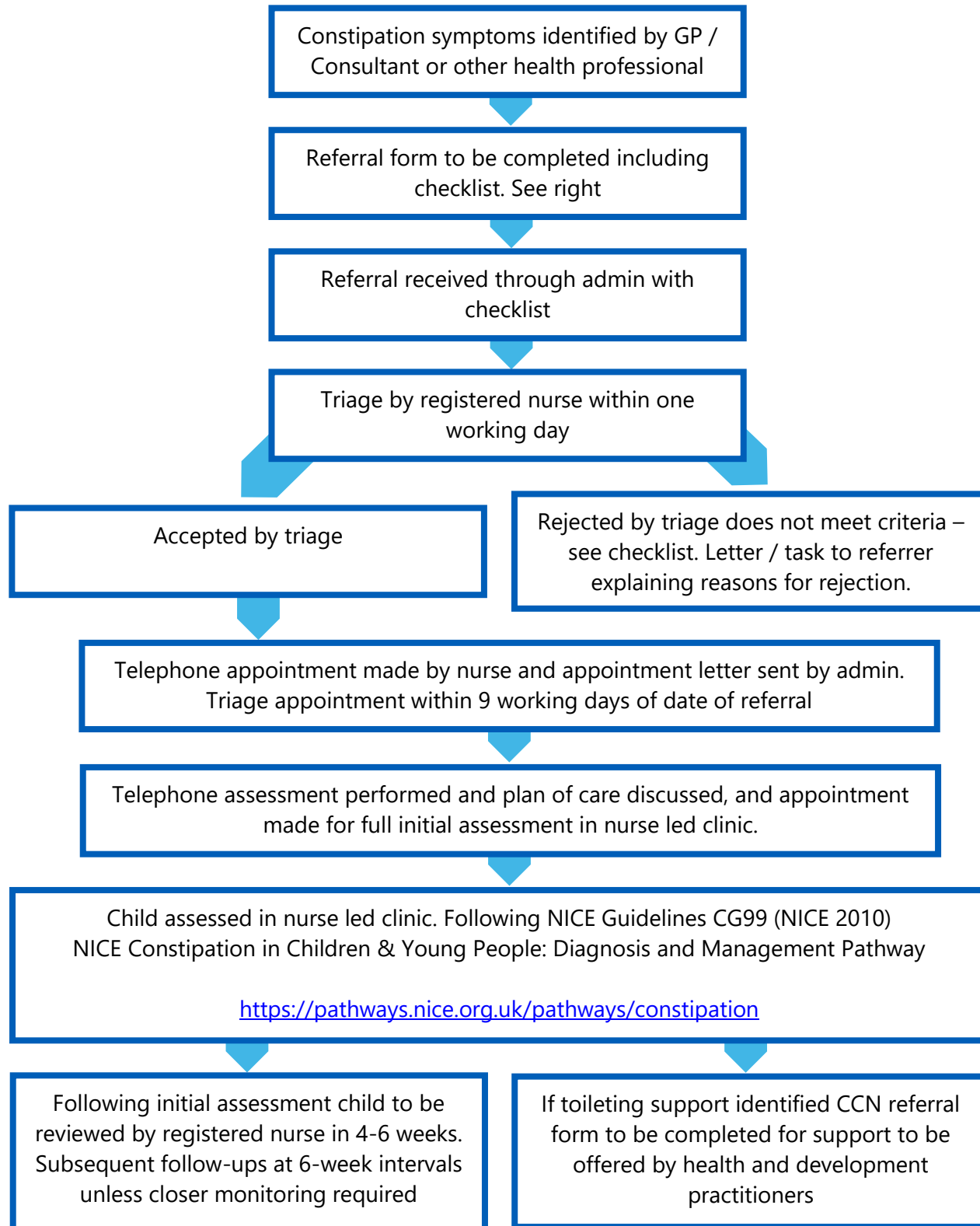
If a child who has Down syndrome presents with a possible infection, have a low threshold for:

- Suspecting serious infections such as sepsis or pneumonia and seek prompt paediatric advice
- Starting antibiotics and continuing them for double the length of time, e.g. 10 days instead of 5 days
- Arrange to review the child, if a viral infection is diagnosed and antibiotics are not commenced.

Please offer the recommended universal immunisations as well as, the Flu vaccine every year from the age of 6 months and the Pneumovax II at the age of 2 years.

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Appendix 11 – Children's Continence Service



If after following the pathway, there is no improvement care to be discharged to the GP with a letter asking for referral to consultant for further investigation

Appendix – Constipation Checklist

CONTINENCE SERVICE CONSTIPATION CHECKLIST

Patient Name: _____ D.O.B: _____

The service will only accept referrals for children with the following criteria:

| | Please Tick |
|---|-------------|
| The child is over 2 years old | |
| The child has received a diagnosis of constipation | |
| The child has been examined by GP or consultant to rule out organic cause for constipation. | |

Prior to referral to the Community Nurse-led Constipation Clinic, the referrer should have completed the checklist below. Please include this checklist with the referral and tick off each box when completed.

| | |
|---|----------|
| Advice has been given to parents/child/young person (if appropriate) to take 6-8 glasses of water/juice (not milk) a day, totalling 2 pints of fluid. Higher intakes of total water will be required for those who are physically active or who are exposed to hot environments. It should be noted that obese children may also require higher total intakes of water. | YES / NO |
| Adequate fibre has been introduced into the diet. Foods with a high fibre content (such as fruit, vegetables, high-fibre bread, baked beans and wholegrain breakfast cereals) have been discussed. | YES / NO |
| Advice has been given about the importance of daily physical activity that is tailored to the child or young person's stage of development and individual ability as part of ongoing maintenance in children and young people with idiopathic constipation. | YES / NO |
| Advised on correct sitting position and implemented a 'good sitting routine' using sticker/reward charts where appropriate. | YES / NO |
| Ensured the family have kept a diary of diet and bowel movements for at least two weeks (attached) | YES / NO |
| Child has been examined by the GP / Consultant or suitably trained health professional. (To include neurological examination, spine, abdominal and perineal area) as per NICE clinical guidelines table 3. to rule out underlying causes for constipation. Should be commenced on Movicol Paediatric Plain on a maintenance dose and taken regularly. | YES / NO |

Appendix 12 – GP Learning Disability Register.

What is learning disability?

The definition of learning disability (LD) can be found here [Learning disabilities - NHS \(www.nhs.uk\)](https://www.nhs.uk). A LD is not to be confused with a learning **difficulty**. This refers to differences affecting academic performance such as dyslexia [Learning difficulties | Mencap](#). Down's syndrome is a common cause of learning disability (LD).

What is the register?

The Learning Disability Register (also known as the QOF Register) records those with LD registered with each UK GP practice. It aims to ensure complete and accurate knowledge about LD in the UK is developed. The information will give a clearer indication about the prevalence and demographics of the lives and deaths of people with LD. Better data should lead to improved planning, commissioning, funding and provision of health and social care services for people with LD in future. It is estimated that there are 1 million people in the UK with LD, only a fifth are currently on the register.

Why be on the register?

- The register helps GP practice staff identify in advance patients who might need extra help or support to access care. The needs of your child/adult when using health services can be discussed. For example, do they need longer appointment times? Or to attend at quiet times? Or to be given Easy Read information about a procedure? These measures are known as "reasonable adjustments" [NHS England » Reasonable adjustments](#). Health services have a duty to make care accessible in this way.
- People with a learning disability are entitled to an **Annual Health Check** when they reach age 14. [annual health check - NHS - NHS \(www.nhs.uk\)](#). If a person is on the register, they will be invited for this from age 14. Most (but not all) GPs offer this service. Link provides additional information about Annual health checks. <https://www.chcpcic.org.uk/chcp-services/wellbeing-service/pages/annual-health-checks>
- Being on the register helps to raise awareness and improve future health care for everyone with LD by contributing to more accurate data collection.
 - Joining the register when young means adjustments and support are established before the person starts using adult services.
- Being registered should mean an automatic invitation for a flu vaccination each year.
- Parent/carers or siblings can be identified by the practice as carers. The LD register has been used to identify those eligible for the COVID vaccine.

How do I get my loved one on the register?

Phone your GP (or receptionist) to check whether they are on the LD Register. If not, then simply ask for them to be put on. If you prefer to write or e-mail your GP to request placement on the register, there is a template letter on the Downright Special website <https://www.downrightspecial.co.uk/resources> to which you can add your own details. The doctor may have recorded that a person has Down's syndrome, but this does not automatically mean they are on the register. You can join the register at any age. If the person is 16 or over they must consent. Mencap have a template Easy read letter which a young person can use to make their own request to the GP along with lots of accessible information around this topic for the young person to look at. <https://www.mencap.org.uk/advice-and-support/health/learning-disability-register>. If your child is 16 + and you feel they do not have capacity to consent to being placed on the register, you can discuss with your GP about making a best interests decision on their behalf using the Mental Capacity Act (2005).

Appendix 13 – Learning Disability Gynaecology Clinic.



Learning disability Gynaecology Clinic



Every 2nd
Wednesday
of the month
8:30am -
12pm noon

conifensexhealth.co.uk



How to get a referral

You can be referred by your doctor, or by contacting **01482 247111**.

When: Every 2nd Wednesday of the month, 8:30am - 12:00pm noon.

A support worker will contact you to get a little bit more information and make sure you get an appointment that is right for you. You will be then sent some handy information about the appointment to make sure you don't forget.

Don't worry if you need a little extra time in the clinic, our team are friendly and caring, and more than happy to help.

For further help or information

Visit conifensexhealth.co.uk

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Leicestershire Partnership NHS Trust Care Down's Syndrome Care Pathway, 2016

Nottingham Guidelines for the management of children with Down's Syndrome

NHS Grampian- Down's Syndrome Care Pathway, 2008

Medical management of children with Down's Syndrome, Marder E.and Dennis J.,
Current Paediatrics (2001) 11, 57 – 63.

Medical and Surgical Care for Children with Down's Syndrome: A Guide for parents
Van Dyke et al (Editors)

Woodbine House. 1995. ISBN 0-933149-54-9

Early Support Programme Publications (Blue Box)

Information for Parents – Down's Syndrome

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/ES13>

Developmental Journal For Babies and Children with Down's Syndrome

<https://www.downrightspecial.co.uk/system/ckeditor/elfinder/files/docs/development/ES13-2010.pdf>

https://www.downrightspecial.co.uk/system/ckeditor/elfinder/files/docs/development/ES49-How_To.pdf

<https://www.downrightspecial.co.uk/system/ckeditor/elfinder/files/docs/development/ES49-Journal.pdf>

Personal Child Health Record for Babies with Down's Syndrome

DSMIG (UK) (2020) Insert for Personal Child Health Record for babies who have Down Syndrome (Fifth Edition, Jan 2020). Available from Harlow Printing or can be downloaded from

<https://www.healthforallchildren.com/wp-content/uploads/2020/02/A5-Downs-charts.pdf>

Down's Syndrome Medical Interest Group

Children's Centre

City Hospital Campus

Hucknall Road

Nottingham NG5 1PB

Website: www.dsmig.org.uk

Down's Syndrome Association

Langdon Down Centre

2a Langdon Park

Teddington TW11 9PS

Tel: 0333 1212 300

Website www.downs-syndrome.org.uk

Parent support, and information on range of issues including health, education and legal.

Issues

Down's Heart Group

PO Box 4260

Dunstable

Down's Syndrome LU6 2ZT

Tel: 0300 1021644

Website: www.dhg.org.uk

Parent support group – useful information leaflets on cardiac issues

Glossary of terms, including abbreviations

0-19 Years' Service

Hull Health Visitors and School Nurses

AFO

Ankle Foot Orthosis (brace worn on lower leg to support ankle)

Amniocentesis

Test carried out during pregnancy to assess whether the baby may have a genetic or chromosomal condition.

Annual Health Check (AHC)

From age 14 onwards someone with Down's Syndrome should have an Annual Health check and Health Action plan via their GP Practice

Audiology

Hearing team

Cardiac/Cardiovascular

Heart/ circulation/blood vessels

Cardiology

Department who deals with health of the heart

Cataract

clouding of the eye lens which can lead to a decrease in vision

ICB

Integrated Care Board (replaced CCGs)

CHCP

City Health Care Partnership
<https://www.chcpcic.org.uk/>

Coeliac disease

Lifelong autoimmune disease caused by a reaction to gluten. It can cause diarrhoea, abdominal pain, bloating and the inability to absorb certain nutrients.

Continence

The ability to control bladder and bowel.

CPAP

Continuous positive airway pressure.

CR

Clear response
(Relating to audiology/ ear/ hearing)

CTLD

Community team for Learning Disability

CVS

Chorionic Villus Sampling

DAFO

Dynamic Ankle Foot Orthosis (brace worn on lower leg to support ankle)

Down's Syndrome Champion

A nominated professional from the 0-19 Years' Service who advises a Health Visitor or School Nurse on supporting a family who have a child with Down's Syndrome

DSMIG

Down's Syndrome Medical Interest Group

Early Support

East Riding service that supports children with additional needs

ENT

Ear, nose and throat team based in the hospital.

EVA

It is a foam-based material, used for insoles.

FBC

Full Blood Count

FISH Test

Fluorescence in situ hybridization test (type of blood test)

Gestation

The length of pregnancy or amount of time a baby is in the uterus (A typical pregnancy gestation is around 38-42 weeks with 'full term' being classed as 40 weeks)

GOR

Gastroesophageal reflux – where acid from the stomach leaks up into the oesophagus (gullet).

HA

Hearing Aid

HUTH

Hull University Teaching Hospital NHS Trust (Services provided at Hull Royal and Castle Hill hospitals)

Hirschsprung's disease

Condition affecting the large intestine and causes problems passing bowel movements.

Hypermobility

Joints are flexible and easily move beyond expected range.

Hypothyroidism

Under active thyroid gland

Infant Feeding Co-ordinator

A professional who specialises in supporting people to feed their baby and advises on different feeding techniques and those who may require additional support.

IPASS

Integrated Physical and sensory service (HULL)

Karyotype

laboratory test done on blood.

Makaton

language programme that uses signs and symbols to help communication. It is designed to support spoken language.

NCR

No Clear Response (Relating to audiology/ear/hearing)

NICU

Neonatal Intensive Care Unit

NIPE

New-born and Infant Physical Examination

Neurodiversity Service

The term neurodiversity covers both 'neurodisability' and 'neurodevelopmental' needs and conditions as defined by NHS^[1] and the National Institute for Health Research^[2]. Neurodiversity is the concept that when it comes

to the human brain/nervous system, people don't all end up the same. In other words, it's a concept that describes uniqueness in cognitive functioning.

The Hull and East Riding Children's Neurodiversity Service

The Children's Neurodiversity service (0-18 yrs.) includes the following services:

- The Front Door Team
- Autism (ASD) & Attention Deficit Hyperactivity Disorder (ADHD) assessment
- Children's Community Team for Learning Disabilities (CTLD)
- Children's Sensory Service
- Children's SEND Sleep Support Service

The Neurodiversity service website provides up to date information for parents and professionals about seeking support or making referral [Hull and East Riding Children's Neurodiversity Service \(humber.nhs.uk\)](https://humber.nhs.uk)

Numicon

multi-sensory approach to teaching maths

OSA

Obstructive sleep apnoea

^[1] <https://www.england.nhs.uk/wp-content/uploads/2013/06/e09-paedi-neurodisability.pdf>

^[2] Informing the NHS Outcomes Framework: evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting

Osteoporosis

medical condition where the bones can become brittle and fragile.

Ophthalmology

Eye/vision team

OT

Occupational Therapy – a team who assess patients and provide therapy, and recommendations.

Oximetry test

test used to measure the oxygen levels in the blood. This may be done overnight as a 'sleep study' to see if the oxygen levels are dropping overnight (which could possibly be due to sleep obstruction or apnoea).

Paediatrician

Doctor who specialises in health of a child

PCHR

Paediatric Child Health Record. The "Red book"

Physiotherapy

Team who looks at physical movement and function of joints, limbs, muscles, posture and core including strength, gait and balance.

Podiatry

Team who specialise in the assessment and treatment of feet, including their position

Portage

Home-visiting educational service for pre-school children with additional needs. In Hull the Family & Setting Support Team (FASS) offer this service

QFPCR

Quantitative Fluorescence-Polymerase Chain Reaction; laboratory test done on blood.

RSV

Respiratory Syncytial Virus

SALT

Speech & Language Therapy. Team advise on speech, communication and dysphagia (mechanical difficulties with eating and swallowing).

SCBU

Special Care Baby Unit

SEND

Special Educational Needs and Disabilities

SLA

Speech & Language Therapy Assistant

TAM

Transient Abnormal Myelopoiesis

Thyroid

Thyroid gland releases important hormones that keep your body functioning at the correct speed.

SaPTS

Sensory and Physical Teaching Service (equivalent to iPass in Hull).