

Integrated Maternity Care Pathway for women with LD:

Learning Disability/Learning Difficulty/Hidden Disability/Autism

1. Definitions

Learning Disability is a significantly reduced ability to understand new or complex information, to learn new skills... with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development ¹

Learning Difficulty describes specific problems processing certain forms of information. Unlike a learning disability, a learning difficulty does not affect general intelligence (IQ). An individual may often have more than one specific learning difficulty (for example, dyslexia, ADHD, dyspraxia are often encountered together), and other conditions may also be experienced alongside each other ²

Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them³. It is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present in different people. The spectrum includes Asperger syndrome and high-functioning autism.

Hidden disability can be a learning difficulty or Autism or Aspergers syndrome; also people with complex medical conditions which affect their intellectual abilities e.g. mental ill-health.

In this care pathway the term LD will be used to describe women with a learning disability or a learning difficulty and/or autism.

2. Background and evidence

It is estimated that 1,191,000 people (2.5%) of the UK population has a learning disability; and only 21% of adults with a learning disability are known to learning disability. ⁴ It is likely that there are a large proportion of people within Leeds with an IQ lower than 70 – 80 points who require additional support but who do not have a formal diagnosis of a learning disability.

¹ Valuing People 2001

² Foundation for People with Learning Disabilities <http://www.learningdisabilities.org.uk/help-information/learning-disability-a-z/l/204300/2016>

³ A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People 2016

⁴ Health Inequalities and People with Learning Disabilities in the UK: 2011

The number of parents with LD is difficult to calculate given that many parents may not wish to divulge they have such a disability and/or may not have a formal diagnosis. Locally, mothers with LD are significantly over-represented in the cohort of women who have their babies removed under the age of one year: 13 of the 38 mothers who had their babies removed in 2012 had a confirmed diagnosis, with a further 7 mothers suspected of having some form of related impairment which had not been formally diagnosed.⁵

Women with a LD can face significant barriers to accessing NHS services, which can contribute to them being less likely to use services, and more likely to access maternity care later in pregnancy. In addition, people with LD experience higher rates of co-morbidity including physical and mental health problems than those who do not have an LD^{6 7} and these increase their risk when pregnant, particularly as they may be unable to follow advice on prevention or self-care.⁸

Approximately 10,000 women birth in Leeds each year. The exact number of women of childbearing age who have a LD is unknown as many will never receive a formal diagnosis. The actual number of women with a LD experiencing maternity care in Leeds is not known, as this data is not currently captured on any maternity systems.

3. **Scope**

This integrated maternity care pathway is aimed at women with:

- ✓ A diagnosed learning disability
- ✓ A learning difficulty
- ✓ Autism
- ✓ Hidden disability

4. **Purpose**

The purpose of the care pathway is to improve the perinatal outcomes for mothers with a LD and their babies. More specifically, to identify and intervene to provide reasonable adjustments to perinatal care to help parents comprehend and adjust to pregnancy and support them to prepare for parenthood.

All women receive perinatal care according to NICE guidance placing the woman, her baby and family at the centre of care. This care pathway recommends additional services and support that is flexible to the individual needs of women with LD. It supports early identification of LD and supports delivery of care through an emphasis on reasonable adjustment, prevention and early support services.

⁵ Maternity Health Needs Analysis for Leeds 2014

⁶ DH 2004

⁷ Jensen et al 2004

⁸ BJOG 2011

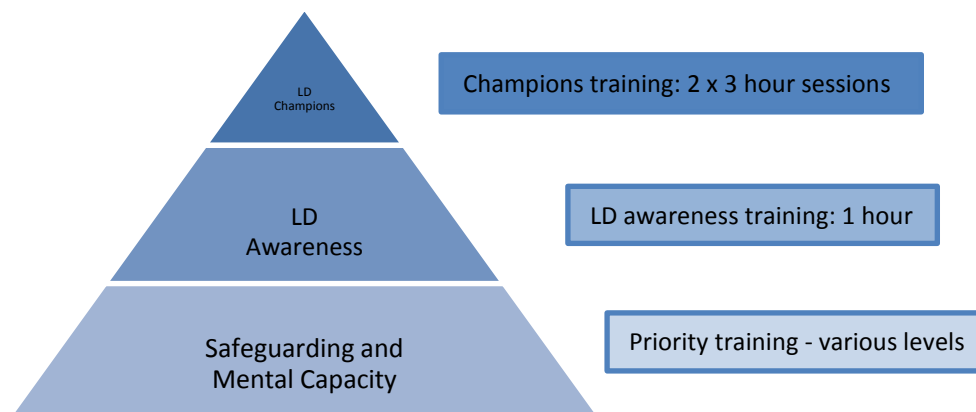
5. Development

This care pathway has been developed via a collaborative multi agency, multi professional group, chaired by Megan Waugh (WHM) and including representatives from maternity services, LTHT and community LD teams & voluntary Sector services in Leeds; facilitated by the Leeds South and East CCG. Women's voices and experiences have assisted in the co-production of the care pathway through a programme of engagement from the outset through to publication.

It is supported by a training and development framework to ensure confident and competent practitioners, who can recognise LD and establish links to other relevant services and pathways.

6. Training to support pathway

A LD awareness training package will be delivered to maternity staff via the Training Calendar and at team meetings. In addition, staff who have volunteered to become LD Champions will receive a 3 hour training package followed by quarterly support sessions delivered by the LTHT Lead Nurse for LD. These staff, who it is anticipated will be working across the maternity service, will provide support to colleagues and signpost them to appropriate services. LD training will focus on Reasonable Adjustments.



7. Reasonable Adjustments

The Law requires us to make reasonable adjustments in the care we provide to ensure that women with LD receive equal standards, access and quality of care as other women do. Examples of reasonable adjustments include: easy read literature; larger format literature; additional time at appointments; support from family or support worker at appointments; referrals to additional agencies (see below), and so on. These reasonable adjustments made in collaboration with the family should be agreed and documented. The Hospital Passport is a useful tool to record reasonable adjustments.

8. **Consent and capacity**

The principles of gaining consent for referral to any other agency should be followed (unless safeguarding issues are identified). The Mental Capacity Act 2005 must be adhered to, namely that a person must be assumed to have capacity unless it is established that they lack capacity; and that a person is not to be treated as unable to make a decision unless all practicable (doable) steps to help them to do so have been taken without success. Therefore, reasonable adjustments may need to be taken to ensure consent is informed and understood.

9. **Evaluation**

The draft pathway has been subject to consultation with all the partner organisations and will be reviewed and evaluated after 6 months. On-going monitoring will include volumes of referrals of perinatal women with LD following the pathway and will be monitored and reviewed through the Leeds Maternity Strategy Programme Board.

Author: Sarah Bennett, Lead Midwife: Maternity Strategy

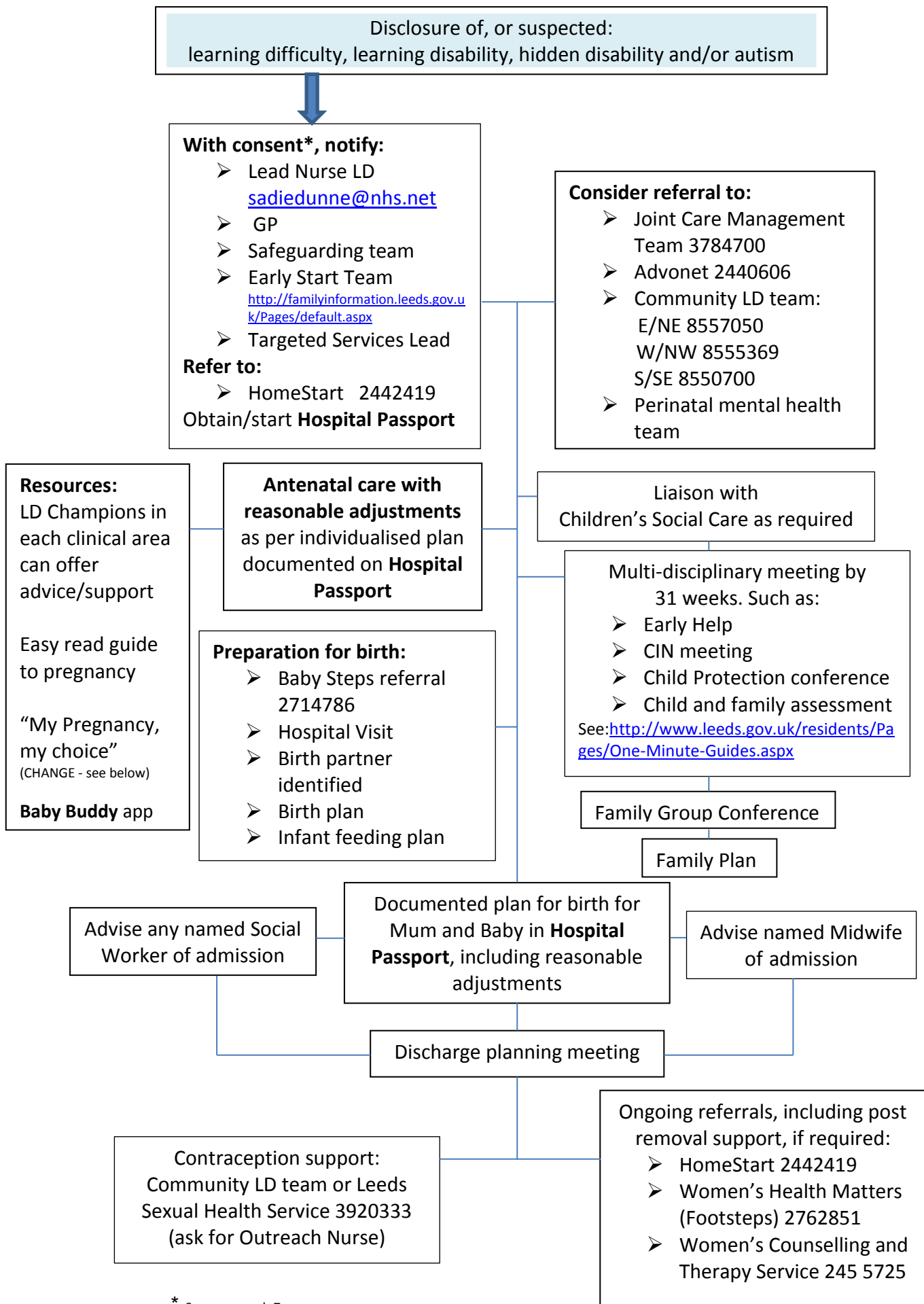
Date: December 2016

Review: December 2017

Reasonable Adjustment considerations

communication needs; advocacy; support; time....

10. The Integrated Maternity care Pathway for women with LD



* See paragraph 7

11. Services to support the pathway

ADVOCACY

Learning Disabilities Advisor: Chapeltown CAB

0113 2849165

The Learning Disabilities adviser provides information, advice and support covering a range of issues and offers a home visiting service throughout Leeds to people with a learning disability and their carer's.

Monday to Friday: 9-4.30pm. The service is delivered from the office in Chapeltown and home visits are also available upon request.

ADVONET - Leeds Advocacy

0113 2440606

Learning disability advocacy supports people to have their needs heard and their rights respected. It both delivers services directly and promotes independent advocacy provided by partners in Leeds and the surrounding area.

DOMESTIC VIOLENCE SUPPORT

Leeds Domestic Violence Service (LDVS)

0113 246 0401

Work with women and men in Leeds giving support, advice and advocacy around a range of issues and is run in partnership by the above Leeds based domestic violence specialist organisations. Groups, outreach, advocacy and resettlement support.

Women's Health Matters

0113 2762851

<http://www.womenshealthmatters.org.uk/>

THE KEY- Group and 1-1 support. Girls and young women experiencing violence/abuse including CSE

CHILDREN'S CENTRES

Throughout Leeds Children's Centres provide a range of services for families with children 0-5, including:

- Family Outreach Workers
- Nursery provision (some CCs)
- Groups
- Advocacy services (CAB)
- Counselling services
- Family Support Services
- Training
- Job Centre Plus outreach worker

Postcode indicator tool for establishing which CC reach area a family live in:

[http://www.familyinformationleeds.co.uk/\(X\(1\)S\(rputzefezegfowinwv4ablmi\)\)/catSearch.aspx?s=UEarlyStart&AspxAutoDetectCookieSupport=1](http://www.familyinformationleeds.co.uk/(X(1)S(rputzefezegfowinwv4ablmi))/catSearch.aspx?s=UEarlyStart&AspxAutoDetectCookieSupport=1)

CHILDREN'S SERVICES

Duty & Advice team

0113 376 0336

One minute guides to Leeds Children's services:

<http://www.leeds.gov.uk/residents/Pages/One-Minute-Guides.aspx>

Over view of services:

<http://www.leedslscb.org.uk/Practitioners/Local-protocols/Early-help-intro/Services-in-Leeds>

HEALTH

LTHT

Lead Nurse Learning Disabilities - Sadie Dunne

0113 2069206 Mobile 07899988703 sadiedunne@nhs.net

Offers information and support, and help in determining what reasonable adjustments may need to be made.

Lead Professional For Mca/Mha And Vulnerable Groups-

Tim Whaley

0113 2066964 Mobile 07788304709 tim.whaley@nhs.net

Provides advice, support and training to LTHT staff in relation to mental capacity.

Leeds and York Partnership NHS Foundation Trust LYPFT

SINGLEPOINT OF ACCESS: 0300 300 1485

Multidisciplinary teams (nurses, behaviour nurses, dieticians, psychologists, psychiatrists) working with people with a learning disability, IQ less than 70.

Area teams: E/NE 0113 8557050

W/NW 0113 8555369

S/SE 0113 8550700

Women's Counselling and Therapy Service

0113 245 5725

<http://www.womenstherapyleeds.org.uk/>

Women's Counselling and Therapy Service (WCTS) offers a low-cost accessible counselling and psychotherapy service for Leeds women on low incomes.

Women's Health Matters

0113 2762851

<http://www.womenshealthmatters.org.uk/>

SEEN – seen, empowered, enabled, noticed - works with groups of disabled women across Leeds providing support and promoting good physical and mental health.

IAPT: Improving Access to Psychological Therapies

0113 843 4388

Leeds IAPT is a group of mental health care providers from the NHS and third sector

<http://www.leedscommunityhealthcare.nhs.uk/iapt/home/>

Monday & Thursday 8am to 6pm

Tuesday, Wednesday & Friday 8am to 4pm

Targeted IAPT:

Touchstone

0113 216 3000

BME targeted support

Community Links

0113 200 9188

17 and 21 year olds targeted support

NSPCC Pregnancy in Mind

0113 2172200

A preventative mental health service for parents-to-be who are at risk of, or experiencing mild to moderate anxiety and depression during pregnancy and the first year after birth. Refer between 15-25 weeks.

<https://www.nspcc.org.uk/services-and-resources/services-for-children-and-families/pregnancy-in-mind/>

HOUSING & FINANCIAL SUPPORT

St Annes Floating Outreach

0113 200 8347

Supported living outreach service. Support people with LD to live a full and active life by enabling and empowering them to live independently as part of the community.

<http://www.st-annes.org.uk/our-services/learning-disabilities/leeds/leeds-floating-outreach-learning-disabilities/>

GIPSIL

0113 2481813

GIPSIL primarily works with vulnerable young people (16-24) providing housing-related support, welfare advice and support to access and sustain employment, education and training.

<http://www.gipsil.org.uk/>

ARCHWAY

0113 383 3900

Provides support to young people aged 16 - 25 from across Leeds. The services on offer are Counselling, Welfare Rights Advice, Employment and Training Support, Housing Support (including Teenage Parent Housing Support), Connexions Personal Advisors (PAs), General Support and Group Work and Activities in the centre

<http://archwayleeds.blogspot.co.uk/p/about-us.html>

Chapelton CAB

0113 2849165

The Learning Disabilities adviser provides information, advice and support covering a range of issues and offers a home visiting service throughout Leeds to people with a learning disability and their carer's. The service covers Welfare Benefits (including benefit checks, help with applications, appeals and tribunals), Housing (repairs, rehousing, etc.), Financial Issues (negotiation, disputes, etc.), Employment and Consumer Issues.

Monday to Friday between 9.00am to 4.30pm. The service is delivered from the office in Chapelton and home visits are also available upon request.

SOCIAL CARE

Joint Care Management Team, Learning Disability Service

0113 247 8880

Technorth, Harrogate Road, LS7 3NB

A Specialist Team, working with people with learning disabilities who have more complex needs, but supporting colleagues in the area teams in Adult Social Care, who work with those people with learning disabilities who do not come to the Specialist Team.

Social Care - Professionals advice line

Children's Social Care

0113 2224409

<http://www.leedslscb.org.uk/Concerned-about-a-child>

SEXUAL HEALTH SERVICE

Leeds Sexual Health Service 3920333 (ask for Outreach Nurse)

PARENTING GROUPS & SUPPORT

Home-Start Leeds

0113 2442419

<http://www.home-startleeds.co.uk/>

Volunteers visit families in their own home regularly (usually weekly) and offer parents and children support, friendship, practical help, a listening ear and encouragement. They also offer practical help, and when necessary they will accompany families to meetings and appointments i.e GP's, Citizens advice, social work meetings, offering the often essential moral support.

Getaway Girls

0113 240 5894

<http://getawaygirls.co.uk/>

Getaway Girls enables vulnerable young women aged 11-25 from Leeds to build confidence, develop new skills and take positive risks in an environment which offers co-operation and support. They offer Group and 1-1 support.

Women's Health Matters

0113 2762851

<http://www.womenshealthmatters.org.uk/>

INCLUDE - provides support, information and advice to young women up to age 19 in Leeds who are pregnant, who are mothers or think they may be pregnant. One to one support, tailored to the young women's individual needs, FOOTSTEPS- Working with women who have had multiple children removed.

YUMS - YUMS Young Mums, Tots and Tums -A social group for young mums and mums to be in south Leeds.

Baby Steps

Nas Draxler 07712217168 babysteps@leeds.gcsx.gov.uk

Targeted perinatal parenting programme, hosted by LCC, delivered by a multi-disciplinary team. Women with LD participate in inclusive groups.

CHANGE

Resources to use when supporting women and families

"My Pregnancy, my choice"

"You and your baby 0-1"

Available to loan from:

The Public Health Resource Library

<http://www.leeds.gov.uk/phrc/Pages/default.aspx>

Technorth

9 Harrogate Road

Chapel Allerton

Leeds

LS7 3NB

Email: phrc@leeds.gov.uk

Useful WEB SITES:

<http://www.easyonthei.nhs.uk/>

<http://www.yourhealthmatters-leeds.nhs.uk/>

<http://www.yourhealthmatters-leeds.nhs.uk/get-checked-out-resources>

Includes screening tool for learning disability

<http://www.improvinghealthandlives.org.uk/about>

<http://www.easyhealth.org.uk/>

Leaflets on health conditions and staying healthy includes a pregnancy leaflet - downloadable:

[http://www.easyhealth.org.uk/listing/maternity-\(leaflets\)](http://www.easyhealth.org.uk/listing/maternity-(leaflets))

[http://www.through-the-](http://www.through-the-maze.org.uk/clients/ttmaze/modules/combined/interface/C)

[maze.org.uk/clients/ttmaze/modules/combined/interface/C](http://www.through-the-maze.org.uk/clients/ttmaze/modules/combined/interface/C)

[OMBINEDMOD_viewlist.aspx?itemtype=all&page=home](http://www.through-the-maze.org.uk/clients/ttmaze/modules/combined/interface/C)

<https://www.mencap.org.uk/about-us>

www.doinggoodleeds.co.uk