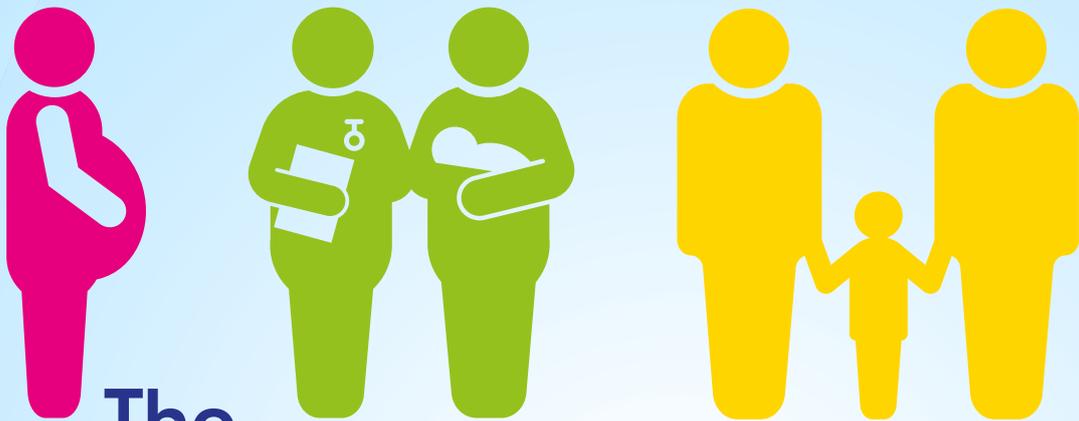


**Supporting the delivery of
good practice in maternity
services for parents with
learning disabilities.**



The **Together Project**

.....
Toolkit & Guidelines

March 2024
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NIHR | National Institute for
Health and Care Research

Introduction

Preparing for a baby can be challenging for anyone, but perhaps even more so for people with learning disabilities. You, as a member of the maternity care team, can make a significant difference to the experience of parents with learning disabilities.

It is estimated that 1.5 million people in the UK have a learning disability¹ and 7% of people with learning disabilities go on to be parents². NHS England and the National Institute for Health and Care Research have funded The Together Project to co-produce evidence-based guidelines and a toolkit to enable you to support parents with a learning disability in a positive, respectful and enabling way. Values underpin our toolkit and are at the heart of all the work we have completed.

To prepare this toolkit we have reviewed existing research, resources and policies to see what works well. We have also interviewed health and social care professionals with recent experience of working with parents with learning disabilities, parents with learning disabilities themselves and their informal supporters/carers about their maternity experiences. Midwives and parents with learning disabilities have used the Together Project resources to support a positive experience of maternity care and we have revised this toolkit in line with their feedback and recommendations.

1. Mencap 2020 mencap.org.uk 2. www.bestbeginnings.org.uk

In this Toolkit, we focus on three elements of practice essential to delivering good maternity care to parents with learning disabilities: identifying need; preparing for parenthood; and supporting the journey to baby and beyond. For each of these three elements of practice, we will provide a **practice discussion** followed by **actions** for you to complete and **questions** for you to reflect on and **discuss** with colleagues. At the end of the toolkit there are useful **resources** or 'tools' to support you in delivering good care for parents with learning disabilities.

We recommend that you work through each element of practice in this toolkit and explore the resources we have identified. You can do this alone but, if possible, work with members of your team. We also recommend that you revisit the toolkit regularly and learn from feedback from your colleagues, people in your care and their family members and friends.

We recommend that you print the guidelines and the Together values and display them for you and your colleagues to refer to when considering how to deliver good maternity care to parents with learning disabilities.

After you have familiarised yourself with the toolkit, you may in clinical practice wish to go straight to the action checklist and questions for reflection. You can print these to record your actions and guide discussions for each parent with a learning disability who you support.

The Together Project was led by the University of Surrey and made possible by the generosity of members of the advisory group whose combined expertise and experience make this guidance possible. We hope you find the contents helpful. [The Together Project Team](#)

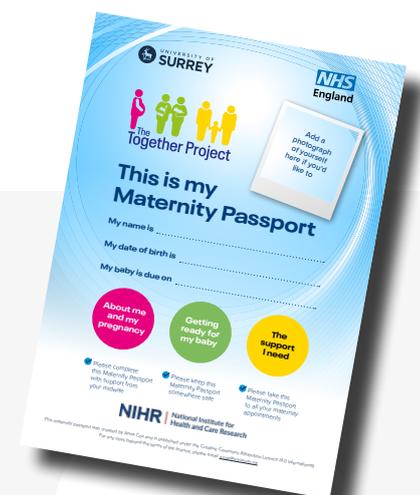
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NOTE REGARDING TERMS WITHIN THE TOOLKIT:

Whilst 'intellectual disabilities' is also used in the field, 'learning disabilities' was the preferred terminology of the Together Project. This toolkit uses Mencap's definition of a learning disability, this is a broad, inclusive definition and was recommended by our advisory group. It states:

*"A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life."*³

The term 'parent' is used within this toolkit to refer to both current and expectant parents. The term 'informal supporter/carer' is used to refer to a person who supports or cares for the parent with a learning disability. This could be a family member, friend, neighbour or other person known to the parent with a learning disability.



[Download
your passport
here](#)

3. Mencap 2020 [mencap.org.uk](https://www.mencap.org.uk)

Identifying Need



How will I know if the parent I am caring for has a learning disability and how will I identify their needs?

Recognising when a person in your care has a learning disability is not always easy. Health and social care professionals interviewed for our project noted that they often had to think beyond diagnoses, to include parents who struggle to learn and retain new information and skills in a way that impacts on their day to day lives. Parents may not have an official diagnosis but can still need support because of a learning disability.

A learning disability may not always be obvious. A parent can present as if they are taking in information but, they may not have understood what is being said. Sometimes a parent will try to hide a learning disability because they fear judgement from others. Sometimes they will not be aware that they have a learning disability.

If a parent appears to have a learning disability, then further conversation can ascertain any reasonable adjustments which need to be considered. Within maternity services, a reasonable adjustment may mean changing the way you provide information or allowing the parent extra time. This is discussed further in the next section on personalised preparation for parenthood. If a parent would benefit from adjustments, this information should be recorded in their hospital notes so that it can be shared with everyone involved in supporting the parent, and there is no need for the parent to repeat their needs.

A learning disability may not always be obvious. A parent can present as if they are taking in information but, they may not have understood what is being said.

Preparation for Parenthood



How can I prepare people with a learning disability to be the best parents they can be?

Parenting can be a challenge for everyone, but perhaps more so for a parent with learning disabilities. As the “Better Births” report states, every woman, every pregnancy, every baby and every family is different and therefore quality services must be personalised⁴. Unless people with learning disabilities are prepared for parenthood in a way that is meaningful to them, they are not receiving a fair opportunity to succeed at raising their children. In the previous section, we looked at ways of recognising the needs of the parent with learning disabilities. In this section we shall look at ways health and social care professionals can, with an

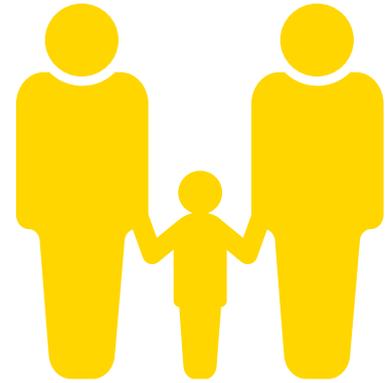
understanding of the needs of each parent, provide personalised preparation for parenthood. The existence of local maternity pathways for parents with learning disabilities are seen as a step towards promotion and optimal implementation of appropriate midwifery care⁵ and are recognised as a feature of good practice⁶. Interviews with health and social care professionals, parents and informal supporters/carers suggest that preparing a person with learning disabilities for parenthood requires potential adjustments to communication, information and the time and space allotted.

Preparing a person with learning disabilities for parenthood requires potential adjustments to communication, information and the time and space allotted.

4. National Maternity Review, 2016 england.nhs.uk 5. Beake, Clark, Turner, & Bick, 2013 doi.org 6. WTPN, 2016 Good practice guidance

Supporting Journey to Baby and Beyond

How can I work in partnership with parents with learning disabilities to support and enable them throughout their journey to becoming parents and beyond?



We know that parents with learning disabilities can and do become good parents, but they require sufficient support to do so. The support needed by parents with learning disabilities may include practical support and emotional support and it may involve a network of health and social care professionals, community organisations, family and peer support. Ideally the support should be available through the parenthood journey including pre-conception, during pregnancy, during the birth and after the baby is born.

The type of support needed will vary from person to person and may change as circumstances change. However, as an optimum response, our guidelines recommend practitioners adopt a proactive and positive approach to providing support. This means working with parents to build on strengths, identify where support may be needed and addressing any gaps in support. The Together Project interviews suggest the importance of trusted relationships with one agenda – a positive outcome for parent and child. This includes

professional groups working together and sharing information in a way that supports parent and child.

The involvement of children's social services should be considered as a supportive measure. Working together also refers to professionals working to build trusted relationships with parents with learning disabilities. Completing the Maternity Passport with the parent can support inter-professional collaboration by enabling each professional to see who else is involved in the parents' support circle. The Maternity Passport will also support identification of gaps in support to alert professionals to necessary referrals.

Parents need to be at the centre of their journey to parenthood, while they need a safety net of support this should enable the parent rather than controlling them. To truly enable a parent with learning disabilities, we recommend a positive mindset is adopted together with a focus on the strengths and capabilities of people with learning disabilities and the belief that with the right support in place they may flourish as parents.

Action Checklist



Things you can do to ensure good maternity care for parents with learning disabilities

	Action	Date Completed
IDENTIFYING NEED	Refresh your understanding of what a 'learning disability' is and the differences between learning disabilities, neurological conditions, autism, mental health conditions and learning difficulties	
	Find out whether you need to make any reasonable adjustments to your practice at the booking in appointment, or as soon as possible if they are later in their journey	
	Record details of the reasonable adjustments required by the parent/s in the maternity notes and in the maternity passport	
PREPARING FOR PARENTHOOD	Check if a local maternity pathway exists for parents with learning disabilities and if so, ensure that this pathway is followed	
	Consider the scheduling, length and environment of future appointments around the needs of the parent/s to make sure they have sufficient practitioner time/contact to enable full explanations and to check understanding	
	Give verbal explanations and/or demonstrations about aspects of pregnancy matched to the needs of the parent	
	Provide antenatal and postnatal information in an appropriate format	
	Discuss suitable antenatal and postnatal education/preparation classes with the parent/s	
	Provide information on safeguarding and reducing risk in an appropriate format	
SUPPORTING JOURNEY TO BABY & BEYOND	Discuss with colleagues and the parent/s whether the involvement of children's social services would support the parent/s to prepare for parenthood	
	If safeguarding concerns have been raised and there is a possibility that the child may be removed, ensure the parents are given appropriate information and support	
	Make the parent/s aware of who their named midwife is and how to contact them, this should be written in their notes and their maternity passport	
	Identify a single point of specialist support and provide the parent with their name and how to contact them, this should also be written in their notes and their maternity passport	
	Provide parent/s with information on who to contact in different circumstances	
	Consider the value of an antenatal appointment with a Health Visitor and set this up for the parent/s if appropriate	
	Discuss with the parent/s their need for advocacy. This should focus on supporting the parent/s as well as safeguarding their child	
	Consider with the parent/s whether third sector support (voluntary/charity groups) is needed and provide parent/s with details	

Questions for Reflection



Points you can discuss with your colleagues to ensure good maternity care for parents with learning disabilities

IDENTIFYING NEED

- Have I considered whether the parent/s require reasonable adjustments to be made, regardless of whether they are known to have a diagnosed learning disability?
- Have I ensured that other factors such as age, poor mental health, being in care etc have not overshadowed the parent/s' need for a different pathway of maternity care?
- Did I adopt a positive mindset, and focus on the parent/s' strengths and capabilities?
- Did I try to get to know the parent/s by asking key questions and listening to their answers carefully?
- Have I given the parent/s a chance to explain to me what they understood from the consultation?

SUPPORTING JOURNEY TO BABY & BEYOND

- Did I adopt a proactive and empowering approach to ensuring the parent/s receive sufficient and appropriate support?
- Am I working together effectively with other professionals. For example am I sharing the necessary information to enable us to provide parent/s with optimum support?
- Have the support needs of the whole family been met? For example, has the other parent (if appropriate) been included in communications and have their needs been addressed?
- Do I know who the specialist learning disability contact is within the trust and have I made contact?

PREPARING FOR PARENTHOOD

- Have I considered whether the parent/s may need more practitioner time?
- Did I ask the parent/s what time of day is best for future appointments? For example, did I ask if they need an appointment at a time of day when they can use a disabled person's travel pass, or whether future appointments need to be optimally scheduled around other commitments such as college?
- Did I ask the parent/s whether they prefer a quiet or low sensory environment for appointments?
- Did I ask the parent/s how they like to be communicated with? For example, did I ask if they prefer short sentences, or visual prompts?
- Have I used any metaphors or figurative speech that may have caused confusion?
- Have I asked the parent/s about their preferred learning style? For example, do they learn best from mirroring, side by side work, videos, conversation, game playing, using apps or social media?
- Did I ask the parent/s about their preferences for information style? For example, whether they like information in easy-read, pictorially, or audio information?
- Have I considered what the best antenatal and postnatal preparation environment would be for the parent/s? For example, would they prefer individual visits, peer support, specialised groups or classes?
- Can they interact well with others or would they prefer one to one support? Is focus an issue, would shorter sessions be better? Would the presence of fathers in the group be an issue?

Values Underpinning Together Project Guidelines



Trust

Trust and honest sharing of information is central to the development of supportive relationships between professionals and parents with learning disabilities.

Open-mindedness

Professionals need to adopt a strengths-based approach and avoid making assumptions and enacting discrimination.

Gentleness

Professionals require a gentleness and compassion as parents with learning disabilities may feel fearful of losing their child.

Enablement

Parents with learning disabilities should be able to exercise the maximum amount of choice and control possible.

Time

Professionals need to allocate sufficient time and space to understand and respond to the needs of parents with learning disabilities.

Humility

Professionals need to listen and learn about the individual needs and experiences of parents with learning disabilities.

Equality

Parents with learning disabilities have equal right to having their needs met by maternity services.

Respect

Parents with learning disabilities should always be treated in an ethical way with respect for their intrinsic dignity.

Together Project Guidelines



To support maternity care for parents with learning disabilities

IDENTIFYING NEED

All health and social care professionals engaging with maternity services require an awareness of what a 'learning disability' is and the differences between learning disabilities, neurological conditions, autism, mental health conditions and learning difficulties but recognising the need for reasonable adjustments could be similar across these groups

The need for reasonable adjustments should be ascertained respectfully at the booking in appointment

The process should be transparent and enable the individual to propose options and solutions

A strengths-based approach should be adopted, acknowledging the person's learning disability but shifting focus to the potential of the individual to parent their child rather than a focus on limitations

Details of reasonable adjustments required should be recorded in the maternity notes.

PREPARING FOR PARENTHOOD

Local maternity pathways for parents with learning disabilities should be developed and followed

The scheduling, length and environment of future appointments should be considered around the needs of the parent to ensure sufficient practitioner time/contact to enable full explanations and to check understanding

Verbal explanations or demonstrations about aspects of pregnancy and care should be given using various resources matched to parent/s' needs

Antenatal information should be provided in an appropriate format

Appropriate antenatal education/preparation classes should be discussed with parent/s

Postnatal information should be provided in an appropriate format

Appropriate postnatal/parenting classes should be discussed with parents

Information on safeguarding and reducing risk should be provided in an appropriate format.

SUPPORTING JOURNEY TO BABY & BEYOND

Adopt a proactive and enabling approach to ensure the parent/s receive sufficient and appropriate support

Consider interprofessional relationships and communication systems, aspire to a common agenda that recognises the support needs of the entire family

Discuss the need for and the availability of specialist support within the trust and the community and reach out as required

Discuss the potential involvement of children's social services to support the parent/s to prepare for parenthood

Identify a named midwife and how to contact them

Identify a single point of specialist support and how to contact them

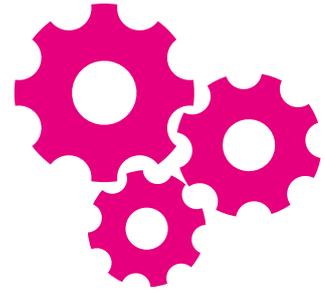
Provide the parent/s with information on who to contact in different circumstances

The value of an antenatal appointment with a Health Visitor should be considered for parents with learning disabilities, and action taken to support this as necessary

Advocacy needs should be discussed and considered. This should focus on both the support required of the parent/s as vulnerable adults and the support required to safeguard their child

Consider whether third sector support (voluntary/charity groups) is appropriate and necessary and direct parent/s accordingly.

Resources to Support Identifying Need



Training to Support Learning Disability Awareness



Oliver McGowan Mandatory Training in Learning Disability and Autism



Core Capabilities Framework for Supporting People with a Learning Disability



A for Adjustment - adjusted care resources to support health and care workers, Health Education England



A module on personalised care in maternity services, supported by the Royal College of Midwives

Many organisations including the Anna Craft Trust, Mencap, Include.org and Disability Matters can provide bespoke training.

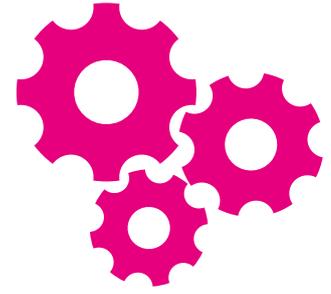
Examples of individual online training:

Exploring learning disabilities: supporting belonging.

An eight session Open Learn (from the Open University) course. Free to access course (sign-up required). The first session explores what is a learning disability.



Resources to Support Identifying Need



Key questions to aid identifying need

The Together Project team suggest the following tips to help identify need:

- Refresh your understanding of what a 'learning disability' is and the differences between learning disabilities, neurological conditions, autism, mental health conditions and learning difficulties
- Allow time, don't rush and speak slowly
- Adopt a positive mindset, focus on the parents' strengths – consider capacity but don't assume it is lacking
- Always say who you are at the beginning, use your name and give your role
- Build trust – ask them what they have been up to today, share suitable experiences from your day
- Get to know the parent by asking questions and listening to their answers carefully
- Once rapport is built you can ask if they feel that they need extra support and if they identify as someone with learning disabilities, if not already identified as such
- Use positive and empowering language
- Highlight what they are doing well.

Some questions you might find useful.

Some of these have been suggested by our interviewees and some have come from checklists compiled by health and social care organisations.

Where did you go to school (was it a mainstream or a special school)?

Did you sit any exams? What grades did you achieve?

Did you learn to drive?

What did you do after leaving school?

Do you attend a day centre?

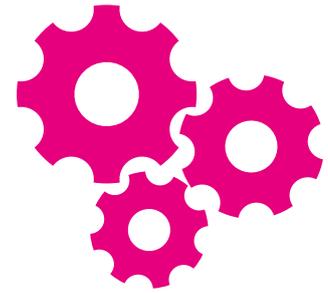
Do you receive any benefits?

Is there anybody supporting you?

Have you ever had a social worker?

(If a good rapport has been established)
– Have you got a diagnosed learning disability?

Resources to Support Identifying Need



Reasonable Adjustments

When making reasonable care adjustments - Consider:

Time – take time to work with the patient

Environment – alter the environment e.g. quieter areas, reduce lighting and waiting

Attitude – have a positive solution orientated focus

Communication – find out the best way to communicate with the patient and also communicate this to colleagues

Help – what help does the patient need and how can you meet their needs.

(TEACH mnemonic created by North Staffordshire Combined Healthcare NHS Trust, adapted from one created by Hertfordshire Community Learning Disability team)

Mencap - Treat me well top 10 reasonable adjustments:

1. Speak clearly with simple words
2. Take your time
3. Work with supporters
4. Be flexible with appointment times
5. Make sure people can get into and around the hospital
6. Provide a quiet place to wait
7. Listen to your learning disability liaison nurse
8. Use hospital passports
9. Provide written information in Easy Read format
10. Always ask the person what they need.



The Equality Act 2010:

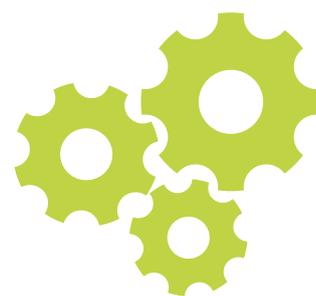
This act states that reasonable adjustments are a statutory duty and health and social care providers must make reasonable adjustments to remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services.



A video on Reasonable Adjustments produced by the Misfits Theatre Company.



Resources to Support Preparing for Parenthood and Beyond



Communication

Mencap guide to communication:



Royal College of Nursing guidance on Dignity in health care for people with learning disabilities

Recommends improvising communication by using simple everyday language, avoiding jargon, considering the use of photographs, pictures or symbols or using Makaton if appropriate.



Examples of organisations working with experts by experience who can help you to co-produce or tailor easy read information.

Include.org



Active Prospects



Information

Baby Buddy App

A free app to support parents providing them with the knowledge, confidence and practical skills to look after themselves and their child.



Easy-read screening tests

Easy-read guides for people with learning disabilities to explain screening tests during and after pregnancy.



Ready for parenthood

Tips, advice and support for new parents.



Having a baby

Book to help parents-to-be with learning disabilities so they can think about what happens during pregnancy and childbirth.



CHANGE

Provides a wide catalogue of easy read and accessible resources for people with learning disabilities, some are free and some for purchase.



Easy Health

Easy read health leaflets and resources, including pregnancy.



Examples of specialist antenatal courses

Parents can normally be referred to these through children's centres or local authorities.

Welcome to the World programme



The Parenting Puzzle workshop



The Working Together with Parents Network

This network supports professionals who work with parents who have learning disabilities. Its members include health and social care professionals, parents and carers. The Network aims to spread positive practice and to promote policy change, so that parents with learning disabilities/difficulties and their children are treated fairly and can get better support. Resources include easy read information for parents with learning disabilities parenting and child protection issues.



The British Institute of Learning Disabilities

This organisation aims to ensure people with learning disabilities are valued equally, participate fully in their communities and are treated with dignity and respect. They have a wide range of resources.



Advocacy services

Every local authority commissions advocacy services for people who need them. As an example, in Surrey, advocacy services are provided by Surrey Disabled People's Partnership (SDPP) in partnership with Matrix. For further details contact your local authority.

Organisations such as Mencap provide information on advocacy:



Elfrida Society Advocacy Services

Specialist Advocates for parents with Learning disabilities and or learning difficulties.



VoiceAbility

Providing people with advocacy in the UK.



Advocacy for All

Providing people with advocacy in the South East of England.



