University of BRISTOL

Esmée Fairbairn FOUNDATION

Working Together with Parents Network (WTPN)
Further update of the DoH/DfES

Good practice guidance on working with parents with a learning disability

We support professionals working with parents with learning difficulties and learning disabilities, and their children.

JULY 2021

The Working Together with Parents Network (WTPN) 2021 update of the 2016 Good practice guidance on working with parents with a learning disability

Foreword

This *Good practice guidance* is not just for professionals involved in child protection proceedings. It contains useful information for anyone working with a family affected by parental learning disability, irrespective of whether any child protection issues have been formally raised.

Timely application of the principles of this *Good practice guidance* may prevent the need for some families to reach child protection stages at all.

Good practice, employed from the outset of any working relationship with parents with a learning disability, is likely to mean that the legal rights of families under the Human Rights Act 1998 and the Equality Act 2010 are respected in a broad range of contexts.

In April 2018, the then President of the Family Division, Sir James Munby, commended 'for careful consideration and application by everyone' the 2016 *Good practice guidance*.[1]

This update retains the structure and substance of that 2016 guidance.

Use the following links to access earlier versions of the *Guidance*:

2016 WTPN update of the *Good practice guidance on working with parents with a learning disability*.[2]

The original DH/DfES *Good practice guidance on working with parents with a learning disability* (2007).[3]

The 2007 *Good practice guidance*

The first *Good practice guidance on working with parents with a learning disability* was published in 2007 by the Department of Health and the Department for Education and Skills. It set out how children's and adult services can and should work together to improve support to parents with a learning disability.

Section 1	Key features of good practice in working with parents with learning disabilities
Section 2	Good practice where safeguarding procedures are necessary

[1] https://www.judiciary.uk/publications/family-proceedings-parents-with-a-learning-disability/.
[2] http://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/2016%20WTPN%20UPDATE%20OF%20THE%20GPG%20-%20finalised%20with%20cover.pdf.
[3] https://webarchive.nationalarchives.gov.uk/20080817163624/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119.

Section 3	Good practice in commissioning
Appendix A	What do we know about the needs and circumstances of parents with learning disabilities?
Appendix B	The policy and legislative framework
Appendix C	Resources
Appendix D	Bibliography

The *Guidance* set out five features of good practice in working with the parents:

- accessible information and communication
- clear and co-ordinated referral and assessment processes and eligibility criteria
- support designed to meet the needs of parents and children based on assessment of their needs and strengths
- long-term support, if necessary
- access to independent advocacy

This update retains that framework.

In 2008, the Joint Committee on Human Rights said in their Seventh Report *A Life Like Any Other*:

> We consider that if the recommendations for good practice in each of these areas were implemented effectively, this could significantly reduce the risk that parents and children would be separated, in breach of the Convention.[4]

The WTPN was recognised in Valuing People Now (2009) and in A Life Like Any Other (2008) as a key dissemination route for the guidance.

Why is the update needed?

To keep the *Good practice guidance* relevant, ensuring it reflects current law, policies, practices and research.

There continues to be a need to press for compliance with the basic principles of the *Good practice guidance*, in order to respect the human rights of parents with learning disabilities and those of their children. It is still hoped that the Department of Health and Social Care will take forward this work, but in the meantime, the Working Together with Parents Network (WTPN) has produced this further, basic update.

[4] Joint Committee On Human Rights, Seventh Report *A Life Like Any Other*, Section 6: Parenting and family life, http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/4009.htm .

Why do the principles of the *Good practice guidance* need to be applied?

Failure to apply the principles of the *Good practice guidance* is detrimental to the children's welfare and amounts to a breach of their and their parents' rights, such as those under the United Nations Convention on the Rights of the Child and the United Nations Convention on the Rights of Persons with Disabilities, the Equality Act 2010 and the Human Rights Act 1998. Parents with learning disabilities must be given every opportunity to show that they can parent safely and be good enough parents, with appropriate support.

For example, given the 26-week timescales and restrictions on expert evidence in care proceedings, together with raised eligibility thresholds for support services and the lack of information about parents with learning disabilities in *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children* (2018) (in contrast to the 2010 version), it is essential that assessments, training and support are both timely and appropriately tailored to the parent with a learning disability.

Lack of a formal diagnosis of learning disability may affect a parent's eligibility for some services but, ultimately, a parent who presents as having difficulty with, or being unable to, read, write, budget, deal with numbers or abstract concepts, process information, retain and apply it etc. will almost certainly require support to enable them to raise their children safely and well.

In the context of child protection proceedings, failure to build in, from the outset, the extra time that a parent with a learning disability needs in order to learn and understand, puts that parent at a significant disadvantage compared to parents without a learning disability.

There must also be joint working across all the agencies (in particular, adult and children's services) and appropriate and effective communication permitting parents to participate fully in the process from the outset, not just at the later court proceedings stage.

All social workers, and family support workers, working with children and families need to be trained to recognise and deal with parents with learning disabilities. The Guidance issued by central government needs to be followed.

Mr Justice Baker in **Kent CC v A Mother [2011]** EWHC 402 (Fam) at para. 135.[5]

---

[5] http://www.bailii.org/ew/cases/EWHC/Fam/2011/402.html.

What changes have been made?

- Contact details and good practice examples have been updated. Obsolete references have been removed.
- Mention is made of the Public Law Working Group's Report (March 2021); the Vulnerable Persons participation in proceedings, Family Court Rules (2017); independent advocacy support; substituted parenting; post-proceedings support.
- Appendix A – research updated to include recent publications.
- Appendix B – legislative and case law updates.
- Appendix C – new resources added.
- Appendix D – new references added and others updated.

Removed references to:	**Replaced by references to:**
Working Together to Safeguard Children 2015	Working Together to Safeguard Children 2018
Information sharing: Practitioners' Guide March 2015	Information Sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers. (July 2018)

CONTENTS

Section 1 Key features of good practice

1.1 Accessible information and communication
1.2 Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways
1.3 Support is designed to meet the needs of parents and children and is based on assessments of their needs and strengths
1.4 Long-term support where needed
1.5 Access to independent advocacy and to support for self-advocacy

Section 2 Good practice where safeguarding procedures are necessary

2.1 Promoting children's best interests
2.2 Ensuring equitable treatment for parents with learning disabilities

Section 3 Good practice in commissioning

3.1 Identifying needs
3.2 Allocating resources – pooled budgets
3.3 Developing services
3.4 Monitoring and reviewing the effectiveness of service responses

Appendix A What do we know about the needs and circumstances of parents with learning disabilities?

Appendix B Policy and legal context

Appendix C Resources

1 Making information accessible
2 Joint protocols and care pathways: good practice examples
3 Resources for working with parents with learning disabilities
4 Assessment tools
5 Person centred planning
6 Parenting skills programmes and resources
7 Legal proceedings

Appendix D Bibliography

Introduction and Executive Summary

What is the purpose of this *Good practice guidance*?

The purpose of this *Guidance* is to:

- help services to improve their support for parents with a learning disability and their children
- increase the chances of the children of parents with a learning disability continuing to live with them in a positive and supportive environment that meets the children's needs.

The guidance is for both adult and children's services. In particular, it is for commissioners of education, health, and social care services, and for all service providers. A key aspect of good practice is multi-agency working and thus this guidance is concerned with social care, health and education services and with the role of both statutory and independent sector services.

Appendix A summarises the research evidence, while **Appendix B** sets out the policy and legal context relating to parents with learning disabilities and their children.

Why is this *Good practice guidance* needed?

As the research summarised in Appendix A illustrates, practitioners often experience some difficulties supporting families affected by parental learning disability:

- Children whose parents have learning disabilities and who are in contact with children's social care services have high levels of needs.
- There is still little evidence of effective joint working between adult and children's services. Children's services practitioners, and adult learning disability workers, rarely have a good working knowledge of the policy and legislative framework within which each other is working. Appendix B therefore sets out the respective policy and legislative framework with the aim of increasing understanding of both the responsibilities of children's and adult social care, and of children and parents' entitlements.

While the same values about safeguarding and promoting the welfare of children should be applied to the children of learning disabled parents as to the children of non-learning disabled parents, such families have specific needs which require particular knowledge and skills if the professionals working with them are to provide an equitable service to these children and their parents.

A specialised response is often required when working with families where the parent(s) has/have a learning disability, but many children and family social workers do not feel adequately equipped to work effectively with them. At the same time, many adult learning disability services struggle to support parents with learning disabilities effectively.

Section 1 of the *Guidance* sets out the key features of good practice, for both children's and adult services, in working to support families affected by parental learning disability.

Section 2 covers good practice where safeguarding procedures are necessary, while **Section 3** sets out some key guidelines for good practice in commissioning services.

The recommendations in this *Good practice guidance* are underpinned by current legislation and statutory guidance for both children's and adult services, and by human rights and equality legislation.

This *Guidance* will assist local authorities to fulfil their public sector equality duty to advance equality of opportunity for disabled people. It will do this by helping to ensure that people with learning disabilities have equal opportunities to be parents, to access appropriate family support services and to bring up their children.

Section 1 Key features of good practice

This section should be read in the context of the following statutory guidance:

- The Care Act 2014 Care and Support Statutory Guidance, Department of Health.
- Working Together to Safeguard Children: A guide to multi-agency working to safeguard and promote the welfare of children, HM Government, 2018.

The following good practice guidance is also relevant:

- Early identification, assessment of needs and intervention – The Common Assessment Framework (CAF) for children and young people: A guide for practitioners, HM Government, 2009.
- What To Do If You're Worried A Child Is Being Abused – advice for practitioners. HM Government, 2015.

The general aims of good practice in supporting parents with learning disabilities and their families are to:

- improve children's wellbeing, in other words to enable them to:
    - be healthy
    - stay safe
    - enjoy and achieve
    - make a positive contribution
    - achieve economic wellbeing

- enable children to live with their parents (as long as this is consistent with their welfare) by providing the support they and their families require.

Good practice is underpinned by the policy, legislation and guidance set out in Appendix B (which sets out the specific responsibilities of both children's and adult services). Legislation and associated guidance set out that:

- children have a right to be protected from harm
- in family court proceedings children's interests are paramount
- children's needs are usually best met by supporting their parents to look after them
- local authorities and all other agencies working or in contact with children have a responsibility to safeguard and promote children's welfare
- parents with learning disabilities have the right to an assessment of their needs for support in their daily lives (no formal diagnosis of a learning disability is required); such assessment should include any assistance required with parenting roles and tasks

- parents should have their assessed needs met where eligible and considering available resources in line with the Care Act 2014 and associated Regulations
- parents with learning disabilities are entitled to equal access to services, including parenting support and information services
- public bodies have a duty to actively advance equality of opportunity for people with learning disabilities and to make reasonable adjustments to policies, practices and procedures, where required.

Good practice is also underpinned by an approach to parenting and learning disability which addresses needs relating to both impairment and the disabling barriers of unequal access and negative attitudes. Such an approach recognises that:

- if the problem is seen as entirely related to impairment and personal limitations, it is difficult to understand how to bring about positive changes for parents and their children
- if the focus is, instead, on things that can be changed (such as inadequate housing) and support needs that can be met (such as equipment to help a parent measure baby feeds), there are many more possibilities for bringing about positive improvements.

When problems are seen as rooted in people's personal deficits and limitations, they may seem intractable and out of reach. Shifting the focus onto features of people's lives that can and should be changed challenges the negative stereotypes that inform such thinking and opens up possibilities for social action in support of families.

Booth and Booth (1997), p.38.

There are five key features of good practice in working with parents with learning disabilities:

1. Accessible information and communication
2. Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways
3. Support designed to meet the needs of parents and children based on assessments of their needs and strengths
4. Long-term support where necessary
5. Access to independent advocacy.

This section covers details of each of these features.

If you've got a parent whose mind is completely preoccupied with, you know, not having enough money, fear, maybe mental health issues, then it's very hard to sort of prioritise and be thinking about your child's needs. So, I would say that a percentage of the parents that we see with learning difficulties and neglect, it's actually because of those broader, social, mental health issues that prevent all parents, actually, from being able to prioritise.

Getting Things Changed (Tackling Disabling Practices: Co-Production and Change)[6]

1.1 Accessible information and communication

Accessible information and communication is crucial to enabling parents with learning disabilities to engage with services and therefore to maximise the chances of children's needs being met. It is also a legal requirement under the Human Rights Act 1998 that parents should be able to participate fully in the process.

1.1.1 All services for parents and children should make information and communication accessible to parents with learning disabilities.

Information about universal services made available to parents and prospective parents should be in formats suitable for people with learning disabilities. This means, for example:

- Easy Read versions of leaflets, letters and other written information
- Audio and/or visual information on CD/DVD/MP3/YouTube
- Fully accessible websites
- Creating opportunities to tell people with learning disabilities, face-to-face, about services for parents and parents-to-be.

Parents with learning disabilities need to hear the message that it is not unusual to require support with parenting, and that information and communication will be provided in ways accessible to them.

Parents need accessible information and communication about relevant services at all the different stages of their children's lives: from midwives and health visitors all the way through to education and youth services.

Communication with schools is particularly important: parents have a responsibility to ensure their children attend and are expected to be involved in their children's education. Parents with learning disabilities cannot fulfil such responsibilities unless information and communication is made

[6] www.bristol.ac.uk/sps/gettingthingschanged/.

accessible by teachers and schools. Unnecessary difficulties are created in parents' relationships with their children's schools if the school does not think carefully about how to communicate effectively with parents and how to involve them in their children's education.

> *The school put their letters on tape. And they gave me stickers to put in each of my children's homework book which I used to say when homework had been done, so I didn't need to sign it.*[7]

1.1.2 Adult learning disability services should take steps to ensure that people with learning disabilities who become parents know about the support available.

Adult learning disability services are well-placed to provide new parents and parents-to-be who have learning disabilities with accessible information about both universal and specialist services. Such information should be made available in all the places that people with learning disabilities are likely to go, including GP surgeries, day centres, colleges, employment projects, supported housing, etc.

1.1.3 Learning disability services should provide accessible information to parents with learning disabilities about their entitlements to an assessment of their need for support with parenting and about the ways in which this support could be provided.

Few parents with learning disabilities are aware of the support they may be entitled to from adult social care services. Attention should be given to providing information about their rights, as this may help to overcome the fear that an involvement with services as a parent with learning disabilities puts them at risk of losing their children into care.

1.1.4 Children's social care should also take steps to ensure that adults with learning disabilities who become parents know about the support available to help them with their responsibilities as parents.

A key barrier faced by children's social care in carrying out their responsibilities is that parents with learning disabilities are often frightened of asking for support when they need it. Accessible, useful information provided by children's social care can go a long way to overcoming this fear.

Independent sector organisations are a particularly important way of getting information to people with learning disabilities as there is less stigma and fear associated with them.

[7] Quotations are from parents with learning disabilities, family members, and practitioners consulted during the course of writing the original good practice guidance and its updates.

I thought that if social services got involved that would mean my children would be put on the child protection register.

1.1.5 When children's and/or adult services carry out assessments, write plans, and provide services to parents with learning disabilities, information should be provided in accessible formats.

Communication is a two-way process; parents with learning disabilities need to be able to understand the information they are being given and be enabled to convey their own thoughts, views and opinions.

Key messages from parents - Social workers who are good at communication:

- are respectful
- turn up on time
- speak directly to parents with learning disabilities
- don't use jargon
- think before they talk to you
- listen and 'hear' you
- explain what is happening
- do what they say they will do
- are honest if they cannot help you
- are patient
- make enough time to communicate with you.

Reproduced with permission from training materials developed by CHANGE and parents with learning disabilities (for more details see Resources section).

Assessments should only be done with informed consent (unless required by the courts). Parents should therefore be given information – in the format suitable to them – about why an assessment is being carried out, what it will involve, and what might happen as a result.

People may misunderstand or misinterpret what a professional is telling them (this is true generally, not just for people with learning disabilities). This may be because they do not understand particular words, or because they have only understood or been told part of the information. People can also pick up messages from body language, which may not be what the professional wants to convey. It is very important to check what someone understands, and to avoid blaming a person for not understanding or getting the wrong message.

Effective, two-way communication is particularly important in meetings involving a number of professionals (such as child protection conferences: see also Section 2). Information and

communication must be accessible. Meetings can be very disempowering for parents. Jargon should be avoided and parents should have someone to support them to prepare for the meeting and take part in it, if this is what they want.

We need people in meetings to have patience and take extra time. It also helps to have someone with you to help explain things. And also for there not to be too many people in the room.

1.1.6 Information and communication should also be accessible to children.

Children also have entitlements to information about services that may help them and their families. They are entitled to be fully involved in any assessment of their needs, according to their age and understanding. They may have their own access needs relating to age and impairment/disability and good practice should ensure that these are addressed.

1.1.7 Those involved in communicating with, and providing information to, parents and children should take advantage of the resources available to make information and communication accessible to people with learning disabilities.

Details are provided in the Resources section of this *Guidance*.

1.2 Clear and co-ordinated referral and assessment procedures and processes, eligibility criteria and care pathways.

Referral and assessment procedures, eligibility criteria and care pathways should prevent avoidable difficulties arising by:

- recognising low levels of need, which, if unaddressed, are likely to lead to difficulties for parents and undermine children's welfare
- recognising support needs at the earliest stages of the parenting experience
- anticipating support needs which may arise at different stages in a family's life cycle.

The challenge for health and social services lies in ensuring that children whose parents are finding it difficult to care for them (i) get enough help and support to assure their safety and well being, and (ii) receive help early enough to minimise the risk of children becoming looked after.

Commission for Social Care Inspection (2006), p.4.

1.2.1 Adult and children's services, and health and social care, should jointly agree local protocols for referrals, assessments and care pathways in order to respond appropriately and promptly to the needs of both parents and children.

These protocols should take into account the processes set out in Working Together to Safeguard Children (2018) (see charts on pages 32–54). The Social Care Institute for Excellence has published guidance and a resource for the development of joint protocols to meet the needs of disabled parents in general.[8]

The process of writing local protocols provides a valuable opportunity for the different services involved to get a better understanding of each other's roles and responsibilities. Some services have developed protocols to cover all parents with additional support needs, others just cover parents with learning disabilities. Some protocols only include adult and children's social care, others also include health and sometimes education and housing.

The following issues should be included, whatever form a local protocol takes and will need to be agreed by the services concerned:

- Referrals
- Sharing information between services
- Provision of accessible information to parents and children
- Assessment responsibilities, including criteria and arrangements for joint assessments
- Provision of assistance/information/advocacy to parents and children to enable them to participate fully in the process and procedures
- Eligibility for different services
- Financial responsibilities, including provision for joint funding
- Charging
- Service provision, including joint working
- Service reviews
- Implementation of the protocol, including training.

Protocols may also cover commissioning, or separate joint commissioning protocols may be required. Good practice in commissioning is addressed in Section 3.

When considering which agencies and services need to agree joint protocols it is important to address the following issues:

- Young parents and parents-to-be with learning disabilities may be in transition between children's and adult services.

[8] www.scie.org.uk.

- Parents with learning disabilities may experience a range of needs and difficulties, including a physical or sensory impairment and/or long-term health condition, mental health problems, domestic violence, substance abuse problems.
- Some parents with learning disabilities experience significant housing problems, including homelessness, harassment from neighbours and difficulties in maintaining a tenancy.

It will therefore be important that local protocols include all relevant agencies and professional roles involved in addressing these issues.

The Resources section of this *Guidance* includes the contact details of some agencies that have agreed joint protocols and are willing to share these.

1.2.2 Attention should be paid to promoting good communication between relevant agencies.

The process of writing and implementing joint protocols should promote good communication between the different agencies concerned. Some other initiatives (which may or may not be part of joint protocols) which have also been found to promote better communication between different services and professionals include:

- liaison posts, e.g. a post within adult learning disability services with specific responsibility to liaise with children's services, or vice versa
- joint training
- practice development meetings or networks involving the range of services and practitioners supporting parents with learning disabilities
- professional consultation services, e.g. designation of a particular children and families social worker to provide professional consultation to adult social care; designation of a community learning disability nurse to provide professional consultation to children's safeguarding teams. One protocol specifies that such consultation will be available within very short time frames in order to react to emergency referrals.

Good practice example

Following a steady increase in the numbers of parents with learning disabilities a Multi-Agency Consultation Group was set up covering South Norfolk. This met monthly to offer support/ advice to professionals/agencies that worked with families where one or both parents may have had learning difficulties. Professionals were offered a 'slot' at the meeting to present a case and the multi-agency team offered advice and, if necessary, appropriate referrals were made.

Source: Thetford Sure Start

1.2.3 Identification of needs should start when a pregnancy is confirmed.

Procedures, criteria and pathways therefore need to be agreed between maternity services and children's and adult social care. Such agreements could relate to parents with learning disabilities in particular, or to all groups of parents and their children who may be identified as vulnerable. An important starting point will be to recognise:

- parents with learning disabilities are entitled to universal services
- universal services are required under the Equality Act 2010 to make "reasonable adjustments" to make their services accessible and suitable for people with learning disabilities
- early, appropriately tailored assessments of support needed to look after a new baby will help to prevent avoidable difficulties arising.

1.2.4 Adult and children's social care services should jointly agree referral procedures to prevent parents and children falling between the two services.

It is good practice that, as a general rule, referrals relating to the needs of parents with learning disabilities should be directed to learning disability services. Where there are concerns about children's welfare a referral should also be made to children's social care. If a referral is made directly to children's services, and it then becomes apparent that a parent has a learning disability, a referral should then also be made to adult learning disability services.

Good practice example

Children's services should consider making a referral to Adult services at the point they believe that a parent, or a parent-to-be, has a learning disability. An early referral may represent the key difference that could keep a family together.

Source: Dorset County Council Multi-agency Protocol for Working with Parents with Learning Disabilities Living in Dorset (Dec 2018)[9]

1.2.5 Eligibility criteria for children's and for adult social care services should enable consideration of each family's needs and circumstances. Eligibility criteria should also enable service responses

[9] https://proceduresonline.com/trixcms/media/4568/108-dorset-multi-agency-protocol-working-with-parents-with-a-learning-disability-july-19.pdf.

at an early stage, to prevent avoidable difficulties arising and to ensure families' legal rights are respected.

Developing joint protocols will give services the opportunity to consider the impact of their eligibility criteria on each other's services. For example, if a parent is deemed not eligible by adult services for support with parenting roles and responsibilities, this may mean that the children's welfare suffers and they become children in need and/or suffer significant harm. The development of joint protocols provides an opportunity to prevent this happening, by ensuring that support is provided at an early stage (as set out in the Care Act 2014 Care and Support Statutory Guidance).

This may mean recognising that a combination of learning disability and parenting responsibilities creates a higher level of need than if needs only relating to learning disability are considered.

Good practice example

In determining eligibility for services the protocol recognises the importance of the parenting role and acknowledges the need to provide additional support to families who may not have met the threshold for certain adult-focused services.

Source: Brighton and Hove City Council *Working Together to Support Parents with a Learning Disability or Learning Difficulty* (2017 Draft)[10]

1.2.6 Local protocols should clearly specify responsibilities for assessment and care planning.

Good practice is promoted where there is clear agreement between adult and children's social care as to the circumstances in which single or joint assessments are required and who should take the lead. For example:

- adult learning disability services have responsibilities for assessment and care planning when there are no child welfare concerns and where the parent needs assistance with the routine tasks of looking after children
- adult learning disability and children's services jointly co-ordinate assessment and care planning where parents need support in the medium to long term to enable them to meet their children's developmental needs
- children's services lead assessment and planning (with specialist input from adult learning disability services) where intervention is required to prevent children suffering impairment to their health or development or significant harm and/or there is a disabled child in the family.

[10] Draft - Working with Parents with a Learning Disability and Learning Difficulty.pdf (brighton-hove.gov.uk).

Whatever level of concern there is about children's welfare, practitioners need to be aware of parents with learning disabilities' legal entitlement to timely and appropriate support, and to ensure that they receive the assessment and service response to which they are entitled.

1.2.7 Services in contact with parents with learning disabilities should use appropriate assessment materials and resources and/or access specialist expertise. Failing to do so will result in the parent receiving an unfair and therefore invalid assessment, in breach of their legal rights.

Needs relating to learning disability should be considered whatever the level of assessment, whether it is an assessment of additional needs being carried out by a universal service using the Common Assessment Framework/Early Help Assessment, or a child in need assessment using Working Together 2018, or a Section 47 enquiry to establish whether a child may be suffering harm.

Where a parent has a learning disability it will be important not to make assumptions about their parental capacity. Having a learning disability does not mean that a person cannot learn new skills.

Learning disabled parents may need support to develop the understanding, resources, skills, experience and confidence to meet the needs of their children. Such support is particularly needed where they experience additional stressors such as having a disabled child, domestic violence, poor physical and mental health, substance misuse, social isolation, poor housing, poverty or a history of growing up in care.

The information gathered for any type of assessment should be no more than is necessary, and multiple assessments should be avoided. People with learning disabilities have often been subject to multiple assessments and may find these intrusive, particularly if they have not had a good experience of service responses to assessment.

Many parents with learning disabilities are understandably very worried that their children may be taken away from them. This fear can create real barriers in establishing the relationship necessary to carry out a good assessment. Consideration should be given as to who is the best person to carry out an assessment and/or what specialist expertise may need to be sought.

It can be worrying to admit to having problems with your child's behaviour, especially if they say he's fine at school and yet you're having problems with him at home.

Diagnostic psychometric assessments can provide information about whether a parent has a learning disability and about their skills and abilities. However, "although such information is useful, it must be stressed that there is no direct correlation between the results of these tests and parental adequacy" (McGaw and Newman, 2005, p.27). A list of such assessment tools is given in the Resources section.

Assessments should cover family and environmental factors, as well as parental capacity. Research tells us that family and community support networks are particularly important for parents with learning disabilities and their children. We also know that parents with learning disabilities are particularly likely to experience difficult housing situations and poverty. Both the Common Assessment Framework/Early Help Assessment and Working Together 2018 require that family and environmental factors are covered.

Adult learning disability services should ensure that person centred planning is made available to parents with learning disabilities as part of both the assessment of their needs and the planned response to these needs. Person Centred Planning is a process of life planning which enables the identification of a person's strengths, needs, relationships and the barriers they face. It is a particularly appropriate method to use where people with learning disabilities are parents (see Resources).

Chapter 6 of the Care Act 2014 Care and Support Statutory Guidance addresses sections 9 to 13 of the Care Act 2014, the Care and Support (Assessment) Regulations 2014 and the Care and Support (Eligibility Criteria) Regulations 2015.

The Care Act duty to assess arises if there is 'an appearance of need'. No formal diagnosis is required.

The statutory guidance states that assessment is one of the key interactions between a local authority and an individual, whether an adult needing care or a carer. The process must be person centred throughout, involving the person and supporting them to have choice and control. It should take a preventative approach and look at a person's strengths.

The guidance confirms the importance of appropriate and proportionate assessment and the need for assessors to be appropriately trained and with the experience and knowledge necessary to carry out the assessment.

Under the Care Act, when assessing eligibility for services, local authorities must consider if the adult has a condition as a result of, for example, learning disabilities. Para. 6.104 of the statutory guidance confirms that the authority should base their judgment on the assessment of the adult and a formal diagnosis of the condition should not be required.

In some areas, adult teams are moving to a functional rather than IQ-based diagnosis i.e. looking at how a difficulty or disability actually affects an individual's functioning on a practical level.

Good practice in assessment of parents with learning disabilities

Care and Support Statutory Guidance, Good Practice Guidance for Clinical Psychologists when Assessing Parents with Learning Disabilities (British Psychological Society), Parenting Assessments for Parents with Learning Difficulties (WTPN) and Person-Centred Planning guidance lay down the foundations for good practice in assessing the needs of parents with learning disabilities.

Whatever the type and level of assessment being carried out, the following are also key elements of good practice:

- Assessors should be knowledgeable about both their statutory responsibilities, and about parents' legal rights, including their entitlements under relevant legislation.
- Where learning disability is suspected, an initial screening tool should be used in order to determine whether a specialist assessment is required (see Resources section).
- Assessors should be sensitive to the stigma attached to a learning disability label. Every effort should be made to frame the issue as one of identifying particular support needs.
- Psychometric assessments should not be relied on as the sole or primary measure of parenting capacity.
- Out-of-home assessments should be avoided if at all possible, unless the home environment is disempowering to the parent.
- Parents should be told, in plain language, what the assessment is, what it is for, what it will involve, and what will happen afterwards. They may need to be told more than once, for example, a parent may need to be reminded what happened at the last meeting.

Close attention should be paid to parents' access needs (this is a legal requirement). These may include:

- putting written material into an accessible format
- avoiding the use of jargon
- taking more time to explain things
- telling parents things more than once.

Beware, however, of the risk of sounding patronising.

Assessments should include the role of significant adults in the parent's life, to establish positive and/or negative contributions to the parenting role and effects on children's welfare.

Assessors should be aware that previous experiences may create significant fear about the role of children's social care services. Parents may be hostile and anxious, and considerable effort may be required to prevent this fear becoming a real barrier to a comprehensive assessment.

Assessors should generally be wary of misinterpreting the effects of cognitive impairment. Advice and specialist input should always be sought when parental learning disability is suspected.

Good practice example

It would be helpful if a referrer describes the difficulties or issues the parent is experiencing rather than specifying a service response. For example, it would be more helpful to describe a situation where the individual is unable to understand essential information (despite best efforts to present the information in a more accessible way) rather than specifically ask for Speech and Language Therapy intervention.

Source: Dorset County Council Multi-agency Protocol for Working with Parents with Learning Disabilities Living in Dorset (Dec 2018)[11]

1.3 Support is designed to meet the needs of parents and children and is based on assessments of their needs and strengths

1.3.1 Support to develop and enhance parenting skills should be suited to the parent's learning needs and circumstances.

Support should be based on, and adapted to, the learning needs of parents. For example, if parents with learning disabilities are to benefit from parenting education programmes – whether run in a mainstream or specialist setting – such programmes will need to be adapted to meet the particular learning needs of the parents concerned (and this, indeed, is a requirement under the Equality Act 2010).

Examples of adapted or specialist parenting programmes include Mellow Futures and Triple P (see Appendix C Resources).

[11] https://proceduresonline.com/trixcms/media/4568/108-dorset-multi-agency-protocol-working-with-parents-with-a-learning-disability-july-19.pdf.

Good practice example

The Community Team for Parents with Learning Disabilities in Stockport wanted to support parents with learning difficulties, where Children's Social Care had concerns about their ability to prepare adequate meals for their children. The team worked together with Adult Education to set up a course on cookery and child nutrition suited to the information needs and learning styles of parents with learning difficulties. Initially Adult Education said that the course could only be certificated if it was assessed through written means, but the team negotiated and worked with them to devise more appropriate forms of assessment. The parents were then able to return to Social Services with certificates to show that they had learned the required skills.

Source: Tarleton et al (2006)

1.3.2 Specialist assessments should be commissioned and undertaken at the earliest point, and not be delayed until proceedings are anticipated or initiated, if they are to have any positive impact on the identification, provision and timely uptake of appropriate support.

Multiple specialist assessments may be needed to identify how best to address the impact of the parent's learning disability on their parenting capacity. This may include, for example, input from Speech and Language Therapists, Occupational Therapists and Clinical Psychologists, but should include, at least, both a specialist parenting assessment and a cognitive/psychological assessment.

It is important to note that specialist parenting assessments such as PAMS (Parent Assessment Manual) and ParentAssess (see Appendix C Resources) are designed for the early stages of intervention to identify appropriate support and to assess the success or otherwise of that support, not simply to demonstrate shortcomings or to assess whether a child should be removed from its family.

Time will be needed to allow the parent to receive and act on the support/training and then be re-assessed. If the initial specialist parenting assessment is delayed until court proceedings are under way, this is likely to mean that the parent will have no/insufficient time to absorb new knowledge and apply new skills.

PAMS is one example of a specialist parenting assessment that can be used at the pregnancy stage. Parents can be more likely to engage successfully before safeguarding or child protection issues are in process and their increasing fear levels hinder their learning.

1.3.3 In the case of parent support services, an assessment of a parent's learning needs and circumstances should inform the support provided to develop parenting skills. Research indicates

that – for parents with learning disabilities – the key elements of successful parenting skills support are:

- clear communication, and ensuring parents have understood what they are told
- use of role-play, modelling, and videoing parent and professional undertaking a task together, for discussion, comparison and reflection
- step-by-step pictures showing how to undertake a task
- repeating topics regularly and offering opportunities for frequent practice
- providing/developing personalised "props": for example, finding a container which will hold the right amount of milk for the child so that the parent does not have to measure out the milk.[12]

1.3.4 A family-centred approach should be taken to parenting support, responding to the needs of all family members (including fathers), rather than just the mother or just the child.

1.3.5 A range of services is required. All families are different, and families require different types of support at different stages of their life cycle.

Families affected by parental learning disability may benefit from some or all of the following types of services:

- Support to use universal ante- and post-natal services
- Parents' groups
- Courses in parenting skills and child development
- Support to use technology e.g. Alexa reminders, alarms, "To Do" lists
- Groups and courses aimed specifically at fathers
- One-to-one support in parenting skills and child development
- Practical support in the home
- Assistance to use direct payments to purchase their own support
- Support with children's social and academic development
- Behaviour support services
- Counselling
- Advocacy services
- Family planning services
- Information and advice to children
- Support foster care/shared care
- Short breaks services.

Those with responsibility for putting together care plans, in response to assessments, need to be able to draw on a range of support services to suit each family's needs and circumstances. The implications of this for commissioning are addressed in Section 3 of this *Guidance*.

[12] Tarleton et al, p.54.

Good practice example

All of the parents spoke warmly of the workers that supported them. They particularly appreciated workers who supported them to do things for themselves. Parents spoke about getting help with daily routines, cooking, budgeting and cleaning their homes. In these instances, workers often came to parents' houses early in the morning and again in the early evening when they particularly needed support. The majority of parents said that "nothing could be better" about the support they received. In most cases the amount of support given had been reduced as parents became more confident in their skills.

Source: Tarleton et al, 2006, p.37

The social worker helped me to get things done like painting and decorating – it made a big difference to how the house felt to live in.

1.3.6 Support services should be available to help parents to promote their child's welfare at different ages and in a variety of situations.

It is against children's interests if support is provided to enable their parents to look after them while they are young but the necessary support is not then provided as children grow older and needs change.

For example, most parents need information, advice and support to help their children if they experience bullying at school or in their local communities. The children of parents with learning disabilities may be more likely to be bullied and their parents may have fewer personal and community resources on which to draw to help children resist bullying and its impact. Advocacy services for people with learning disabilities can be an important source of support, where these are available, but it is also necessary for schools and other services to think about how parents with learning disabilities can be helped in these circumstances.

Many parents need help with parenting adolescents and parents with learning disabilities may need access to support which recognises the impact of their learning disability. Parents with learning disabilities are entitled to expect that organisations that provide support with parenting teenagers make the necessary reasonable adjustments so that they can use such services. They and their adolescent children may also need access to specialist parenting support.

The child psychologist saw all of us, the whole family, first. Then he saw my son on his own. And then he told us how to do things to encourage good behaviour. It made a big difference, [my son] got a lot better and he's much happier.

1.3.7 Where a number of different agencies are involved in supporting families affected by parental learning disability, a consistent and co-ordinated approach should be taken to the aims and objectives to be achieved.

Parents with learning disabilities are often in contact with a range of different organisations and professionals, and in these circumstances sometimes receive conflicting messages about what they should be aiming for. A lack of consistency and co-ordination confuses parents, is fundamentally unfair and places them at an unnecessary disadvantage, which, in child protection proceedings, could seriously affect their chances of keeping their children.

Good practice example

Our focus is understanding what best we can do to optimise how this parent can successfully parent. We support other professionals to understand the assessments, the parent, and the impact of their learning disability and other diagnoses on their parenting and engagement.

Annie – some of the professionals felt she was deceptive and manipulative. She agreed to everything but didn't follow up; she missed appointments. The SALT, PAMS and cognitive assessments offered alternative interpretations of her behaviour and reactions, as a result of which better co-ordination and communication between the professionals meant fewer people involved, more visual aids, appointments made for the same time, same day each week. Annie was able to carry out everything asked of her. Concerns were stepped down to child in need level.

Bekki – her two previous children had been removed, she had been diagnosed with learning disability and was struggling with mental health issues. She had a good relationship with the Occupational Therapist from the special parenting service, based in a learning disability team. The OT co-ordinated, providing advice and support to other professionals working with Bekki, explaining the cognitive assessment to them and how its findings contextualised the mother's understandings and interactions with them.

Source: A Clinical Psychologist and a Speech and Language Therapist from a local authority taking part in the Getting Things Changed project, www.bristol.ac.uk/sps/gettingthingschanged/.

1.3.8 Children should be provided with support in their own right.

The children of parents with learning disabilities may need support in their own right. For example, their health or developmental needs may suffer while their parent is learning to better meet these needs and/or parent support services are being put in place. Children, particularly older children, may be at risk of taking on inappropriate caring roles within the family, or their welfare may be threatened by inadequate parental supervision. In such situations, children will meet the 'child in need' criteria and adult and children's services should work together to address children's needs, while at the same time work is done with parents to increase their capacity to meet their children's needs. Neither intervention is a substitute for the other but should be provided in tandem.

Good practice example[13]

Jake is 13 and lives with his mother and two siblings, all of whom have learning disabilities (Jake does not). Jake's social worker felt that he didn't have sufficient opportunity at home to do his homework, as his mother relied on him to help with his younger brother. She was also concerned that he didn't spend much time with friends his own age. She arranged for him to attend an after-school homework club on three days a week and to go to a football club every Saturday morning. The adult learning disability team re-assessed his mother's support needs and provided some additional help with preparing supper for the three children.

1.3.9 Parents may need emotional support.

Parents with learning disabilities may have low self-esteem and lack confidence because of previous life experiences. They may therefore need support to build their confidence.

Parents may particularly need emotional support when children's social care become involved because of concerns about children's welfare. Fear that children are going to be taken away can make it harder for parents to respond positively to assessments and interventions. In such circumstances, parents need support from someone who they feel is "on their side" and who can help them positively engage with services. Such support is often provided by adult learning disability services, and especially by independent sector services and advocates.

[13] Good Practice examples concerning individual families are anonymised descriptions of cases provided by some of the services consulted.

Messages from parents:

- Listen to children.
- Help children to understand what a social worker is and what their job is.
- Help the children say what they want to say.
- Recognise positive changes, even if they're very small.
- Put judgements in the background. (We know you're judging us but don't behave like you are when you're talking to us.)
- Help us to understand how the system works and who does what.
- Put in support workers to help us get the children to school on time and things like that.
- Build up trust so that we feel OK about letting you into our house and sharing information with you.
- Don't patronise us.
- Believe that we can change.
- Acknowledge what we are doing, not just what we're struggling with.

Source: Taken from a meeting with parents with learning disabilities in Bristol.

1.4 Long-term support where needed

You don't wake up and not have a learning difficulty. We have a mind-set within learning disability services – we are generally there for life.

Social worker in a community learning difficulties team,
quoted in Tarleton et al, 2006, p.31

1.4.1 A need for long-term support does not mean that parents cannot look after their children. Some parents with learning disabilities will only need short-term support, such as help with looking after a new baby or learning about child development and childcare tasks. Others, however, will need on-going support. Most may need support at various points of their family's life cycle for two main reasons.

First, although a parent with learning disabilities can learn how to do things, their cognitive impairment will not go away. Just as someone with a physical impairment may need personal assistance for the rest of their life so a person with learning disabilities may need assistance with daily living, particularly as new situations arise. Second, children and their needs change. A parent

may have learned to look after a baby and young child and be coping well. However, as the child enters adolescence other support needs may arise.

Good practice example

Janine had a positive relationship with all the workers she has been involved with over the past five years. She says they "sat down and talked to me". Even though there are now no concerns about her daughter's welfare, she is still in frequent contact with the health visitor and knows she can ring them or the worker from the specialist parenting services if she needs help or is worried about something.

Source: Getting Things Changed project[14]

1.4.2 Where a need for long-term support with parenting tasks is identified, it should form part of the parent's Care Act support plan and/or child in need plan.

Early identification of support needs will help prevent unnecessary difficulties arising, but it should be recognised that some support needs may be on-going, and this should be reflected in care planning.

Good practice example

Della had a learning disability. She had had three children taken into care and didn't know how to ask for help from people or services. Then she met Dean, and they had a baby. Connecting Parents successfully advocated for them to keep their child; Della and Dean were connected to another couple who had good values and wanted to support the family as a whole. Dean had said that he wanted more input into the parenting and so was supported to attend a group for Dads. He also got a voluntary job helping the council to look after their gardens.

Della and Dean are now out of crisis and connected to their local community in a positive way. They are in contact with Connecting Parents through their increased network of friends and know where to seek help when they need it. (2015) Source: http://www.grapevinecovandwarks.org/

[14] www.bristol.ac.uk/sps/gettingthingschanged/.

1.4.3 Practitioners should aim to build a relationship with parents where they feel able to ask for support as needs change.

Children's welfare is more likely to be effectively promoted if parents feel that practitioners are seeking to work in partnership with them to improve outcomes for their children, and if they experience positive responses to their needs.

1.4.4 In a number of cases, courts in England have accepted the local authorities' position that the amount of long-term support needed equated in effect to 'substituted parenting', which was considered to be harmful to the welfare of the child(ren), therefore resulting in the permanent removal of the children from their parents.

Where a local authority raises the issue of 'substituted parenting' it should be able to fully evidence its position, including an analysis of the weight and likelihood of the risk and the options that have been considered to address, reduce, or remove that risk.

Every effort should be made to support, not supplant the parent.

Good practice example

Consider parents' caring responsibilities when care planning for adults with a learning disability/difficulty or autism so support packages do not disrupt the parent/child relationship.

Source: Brighton and Hove City Council *Working Together to Support Parents with a Learning Disability or Learning Difficulty* (2017 Draft) [15]

Any care and support provided should be focused on enabling the parent to become as independent as possible, facilitating the parent to confidently develop skills that will enable them to parent safely and effectively.

Source: Dorset Council *A Multi-agency Protocol for Working with Parents with Learning Disabilities Living in Dorset* December 2018 (updated July 2019).[16]

1.5 Access to independent advocacy and to support for self-advocacy

1.5.1 Self-advocacy support should be made available to parents to help to build confidence and self-esteem.

Lack of confidence and low self-esteem can create parenting difficulties – poor hygiene can be associated with low self-esteem for example, or a parent may fail to attend a mother and baby

[15] Draft - Working with Parents with a Learning Disability and Learning Difficulty.pdf (brighton-hove.gov.uk).
[16] Black info sheet - portrait (proceduresonline.com).

group because of a lack of self-confidence. A self-advocacy group can help boost self-esteem and confidence, and thereby encourage the development of parenting skills. Such support can also help parents develop strategies for coping with harassment and bullying.

1.5.2 Independent advocacy and self-advocacy support should be made available at the earliest stage to help parents access and engage with services from the outset. Failure to do so may make it difficult to argue that the parents have been able to participate fully in the process from the start (as is their legal right), that they have understood what the concerns are and what they needed to do to address those concerns.

This procedural unfairness may amount to a breach of the family's legal rights, particularly if it adversely affects the chances of the child(ren) remaining in the care of their parents.

Parents with learning disabilities often struggle to be given an independent advocate at any stage earlier than the formal, legal initiation of the pre-proceedings stage, which can be many months after the first involvement by children's services and much too late in the process for the parent.

Local authorities sometimes make a distinction between advocacy needed by parents and the provision of 'statutory advocacy' by which they mean advocacy they are required to provide under the Mental Health Act 1983, Mental Capacity Act 2005 and the Care Act 2014. However, in the context of parents with learning disabilities, it is worth noting that in addition to the Care Act, other statutes are equally relevant to the provision of advocacy support, such as the Human Rights Act 1998 and the Equality Act 2010.

The Care Act 2014 imposes a duty on local authorities to provide an independent advocate where an individual would otherwise have substantial difficulties in being involved in processes such as their own assessment and care planning. (See chapter 7 Care and Support Statutory Guidance for full details.)

The Equality Act 2010 imposes a duty on local authorities to make reasonable adjustments so as to eliminate discrimination and to advance equality of opportunity; the provision of an independent advocate may assist with this.

The Human Rights Act 1998 entitles a parent to participate fully in the process; this includes stages prior to any formal legal proceedings being initiated.

Parents with learning disabilities may experience difficulties in getting access to housing which is suitable for them and their children. In such circumstances they may well need self-advocacy skills and/or advocacy support in their dealings with housing providers. They may also need assistance ensuring they and their family receive the benefits to which they are entitled.

Parents with learning disabilities sometimes have a long history of difficult relationships with children's social care, particularly if they have had previous children removed from their care. These experiences can create hostility, a feeling of a lack of control, and a reluctance to engage with services. Independent advocacy and support for self-advocacy can help parents to

understand professionals' concerns, while at the same time giving parents knowledge about their rights and responsibilities and confidence to state their needs.

Advocacy support may also be necessary if a parent is to give informed consent in respect of a service intervention – especially where informed consent is a legal requirement.

1.5.3 Commissioning strategies should address the availability of local advocacy (see Section 3 of this *Guidance*) in order to comply with statutory duties under the Care Act 2014, the Equality Act 2010 and the Human Rights Act 1998.

It is important that the advocates have the appropriate skills and knowledge of both learning disability and child protection issues when working with parents with learning disabilities.

Good practice example

Parents with a Learning Disability and/or Autism – Self-assessment on service delivery in line with the *Good practice guidance* (2016)

Swindon Advocacy Movement working with Swindon Borough Council used a RAG (Red, Amber, Green) system, self-assessment table to address issues such as data collection and analysis, culture, communication, the referral and assessment process, support, future services and priorities, enabling a detailed audit of how well a service is working with parents with learning disabilities.

For further details, contact Swindon Advocacy Movement – Colette O'Sullivan, Children and Families Advocacy Manager. Email: secure@swindonadvocacy.co.uk Tel: 01793 542266.

The next section of this *Guidance* covers situations where safeguarding procedures are considered necessary.

Section 2 Good practice where safeguarding procedures are necessary

This section should be read in the context of the following guidance:

- Working Together to Safeguard Children: A guide to inter-agency working to promote and safeguard the welfare of children (2018) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/779401/Working_Together_to_Safeguard-Children.pdf
- Information Sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers (2018) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721581/Information_sharing_advice_practitioners_safeguarding_services.pdf
- Protocol on Advice and Advocacy for Parents (Child Protection) (2002) http://www.frg.org.uk/images/PDFS/advocacy-protocol.pdf
- National Standards on the Provision of Children's Advocacy Services (2002) https://article39.org.uk/wp-content/uploads/2019/02/National-advocacy-standards-Nov-02.pdf
- Independent Advocacy in Child Protection – Guidance for Policy Makers, NCB (2013) Independent-Advocacy-in-Child-Protection.pdf (article39.org.uk)

Where there are concerns that children of parents with learning disabilities are at risk of significant harm, good practice will be promoted by:

- clarity about rights, roles and responsibilities, including the legal basis for action and the entitlement of parents to support under both children's and care legislation
- in-depth assessments, including appropriate specialist input from both children's and adult services
- timely and effective information sharing between relevant agencies and professionals
- timely and effective involvement of parents and children, and the provision of independent advocacy.

2.1 Promoting children's best interests

Children have a right to be protected from harm and for their welfare to be prioritised. They also have the right to receive the necessary support in order that, wherever possible, they remain living with their parents.

2.1.1 Local authorities have a duty, under the Children Act 1989, as amended by section 53 of the Children Act 2004, to ascertain the wishes and feelings of children when carrying out assessments and making decisions about service responses.

To do this sensitively and effectively, those ascertaining the children's views should have some knowledge and understanding of the impact of learning disability on the parent's ability to parent, so that they can explain this appropriately to the child/ren and better understand the child/ren's perspective.

Children also have the right to information at all stages of the safeguarding process, from the outcome of section 47 enquiries through to court proceedings. Consideration should always be given to how to make such information accessible to children, and to the need to provide the information more than once for children to make sense of it.

2.1.2 Where section 47 enquiries conclude that a child is not at risk, or not at continuing risk, of significant harm, it will be important that, where appropriate, action is taken – under section 17 of the Children Act 1989 and care legislation – to prevent future problems arising.

It is particularly important to avoid the situation where poor standards of parental care, which do not, however, meet the threshold of significant harm to a child, subsequently deteriorate because of a lack of support provided to the parent. A failure to provide support in this type of situation can undermine a child's right to remain with their family. It is also important to provide any necessary support when a child is no longer the subject of a child protection plan, in order to prevent a subsequent deterioration in parental care (see 2.2.6 and 2.2.11 below).

2.1.3 Where a child protection conference is convened, a child should be invited and supported to participate, subject to their age and understanding.

The chair should meet the child beforehand to explain the process to them and an independent advocate should be provided where appropriate. Where it is not appropriate to involve a child in the conference, children's social care should ensure that the child's wishes and feelings are conveyed to the meeting. It is good practice to avoid the situation where one worker is representing the views of both parents and children.

2.1.4 When a key worker is appointed for a child whose parent has a learning disability, it is important that the worker has some understanding of learning disability or, if not, that the worker has access to such expertise, if the child is to be properly supported.

2.1.5 Children who are provided with accommodation under section 20 of the Children Act 1989 by a local authority are entitled to independent advocacy services.

This means they should have access to an advocate who works for them and no-one else and who helps to ensure that they:

- understand what is happening to them
- can make their views known

- where possible, exercise choice when decisions are being made about their care.

Section 7 (Local Authority Social Services Act 1970) guidance (due to be updated in 2021) sets out the standards for children's advocacy services (Department of Health, 2002a). It is important to ensure that the children of parents with learning disabilities have equal access to independent advocacy services.

2.1.6 Local authorities should promote contact with family members for children who are the subject of care orders, unless the court has given them permission to refuse contact.

Children's wishes and feelings about contact with their family should be taken into account, including the venue and timing of contact. In most cases, it will be in a child's best interests for them to maintain links with their family, however occasional this contact may be and even where there is no prospect of the child returning to their family. It is in children's best interests if their parents are supported to avoid conveying negative and/or contradictory messages about substitute carers.

Continuing contact with siblings, grandparents and other family members is usually in a child's best interests and should be promoted whenever it is in the child's best interests.

2.2 Ensuring equitable treatment for parents with learning disabilities

Parents and children have a right to a private and family life. Children also have a right to protection from harm.

2.2.1 Parents whose children are the subject of section 47 enquiries should always be given early information about independent sources of advice and advocacy, both locally and nationally.

2.2.2 It will be important that every effort is made to ensure that independent advocates are those who have the necessary skills and expertise concerning both learning disability and child protection.

Informal supporters should be provided with advice and information, or referral to relevant organisations, to help them carry out their role effectively and constructively.

2.2.3 Unless sharing information would place the child at risk of significant harm, parents should be fully informed about, and involved as much as possible in, the whole process, from the outcome of section 47 enquiries through to court hearings.

They should be provided with whatever assistance may be required to enable them to understand what is happening and to express their views. Information should be provided in a format which is accessible to them. It should be recognised that information may well need to be provided more than once in order for parents to understand what is going on.

It is good practice to identify – at an early stage – someone or another agency who can help the parent understand what is happening and to contribute to assessments and, where possible, to care planning. Such support can be crucial to gaining parents' co-operation and can help to avoid, for example, having to go to court to obtain a Child Assessment Order.

2.2.4 Core assessments involving families affected by parental learning disability should always include specialist input concerning the impact of learning disability. For example, input from a Speech and Language Therapist to identify how best to communicate with the parent.

Core assessments should also include seeking information from others who may know the parent(s) well, providing the parent gives their consent.

It should be recognised that, in many cases where there are risks of significant harm to children of learning disabled parents, parents usually face other difficulties in addition to learning disability. These may include mental health and/or physical health problems, domestic violence and substance abuse. Assessments should therefore also include, where appropriate, specialist input on these issues.

2.2.5 Where it is a partner (who may or may not have a learning disability themselves) of a learning disabled parent, who poses a risk of harm to the child, it will be important to seek to support the non-abusing parent to protect their child.

Assessments should also address the possible vulnerability of the learning disabled parent and their own need to be protected from harm. Specialist input to assess and meet the needs of a vulnerable adult may be required. (See also chapter 14 (Safeguarding) in the Care Act 2014 Care and Support Statutory Guidance.)

2.2.6 Where section 47 enquiries conclude that a child is not at risk, or not at continuing risk, of significant harm it will be important that action is taken to prevent future problems arising.

It is particularly important to avoid the situation where poor standards of parental care, which do not, however, meet the threshold of being of significant harm to a child, subsequently deteriorate because of a lack of support provided to the parent. A failure to provide support in this type of situation can undermine a parent's rights to a private and family life and may also contravene an authority's disability equality duty.

Families affected by parental learning disability are likely to have an on-going need for support, and where a child protection plan is not considered necessary, a child in need plan should be drawn up for each identified child in need, drawing on the good practice identified in Section 1 of this *Guidance*.

2.2.7 Parents should be invited to attend child protection conferences and support provided to enable them to participate fully, in accordance with their legal right.

Chairs of child protection conferences should meet with the parent beforehand to explain the process to them and there is an expectation that they will be provided with an independent

advocate if this is what they wish. The extended family can often play an important role in supporting parents with learning disabilities and they should be invited, if the parent so wishes.

Careful consideration should be given to ensuring that all communication associated with the child protection conference – from invitation and the conduct of the meeting through to the minutes/notes of the meeting – is accessible to the parent with learning disabilities. Information should be sought, from the parent and/or their advocate, about what communication format is accessible to them.

Good practice example

One child protection conference chair always asks for a parent's 'word bank'. This includes the words that parents can read and understand. All subsequent letters to parents and any papers they need to see, then have to be written using words in the 'bank'. The 'word bank' is drawn up by the parents and a trusted professional before the child protection meeting.

Source: Tarleton et al (2006), p.86

2.2.8 Where children are subject to a child protection plan, it is good practice to appoint a key worker for the parent(s) with learning disabilities, as well as a key worker for the child/ren.

Both key workers should be part of the core group and should have expertise, or access to expertise, in supporting families affected by parental learning disability.

2.2.9 Extended family members should be part of the core group, if the parent wishes this and if they have a role to play in supporting the family.

Where friends or family members are helping to support a parent with learning disabilities, in the context of child protection procedures it is good practice to provide information and advice to such supporters to enable them to fulfil this role effectively. They may be referred to specialist advice services, such as the Family Rights Group, or to relevant local independent organisations; and/or they may be given information about the child protection process and their potential role within it.

See section on the involvement of supporters in *Protocol on Advice and Advocacy for Parents (Child Protection)*, Department of Health (2002), p.27.

2.2.10 Where a child protection plan is drawn up and this involves action to be taken by parents, the chair should ensure that parents are fully supported to understand what is required of them and that support is provided to help achieve this.

This may well involve working with adult learning disability services and/or an independent sector agency. Parents should only be judged on whether they have complied with any requirements if it can be shown that:

- they were given clear information about what was required of them
- the necessary support has been made available to them.

Good practice example

The family had been doing really well, with the father taking on the role of main carer to mother and baby. But when the baby turned one, they realised they needed some support and went to the GP, who referred them to social services. Over the next four years, 13 social workers worked with the family, each doing their own assessments and focusing on the mum's learning difficulties rather than providing the help needed. This was very distressing to the family as a whole, making parenting even more of a challenge and making mum and dad feel intimidated, powerless, confused and exhausted. As a result, mum suffered from depression and was prescribed antidepressants.

At this point, the voluntary organisation got involved and worked with the family for a number of weeks, attending court, core meetings and a case conference, as well as visiting their home a number of times. They also supported the couple to create their own Person-Centred Plan, which helped them begin to take control.

"We have never had such positive things said about our family; it has given us the confidence to continue to do the best for our child."

Source: Circles Network Website (2016)[17]

2.2.11 When a child is no longer the subject of a child protection plan, it is important that support to parents is continued according to assessed need.

There is a danger that high eligibility thresholds in children's social care can mean that support is withdrawn. This may mean that parents struggle to maintain improvements in their parenting capacity and they enter a 'revolving door' of re-referrals which may mean their children being

[17] https://circlesnetwork.org.uk/.

looked after by the local authority. The involvement of both children's and adult services in providing services to members of the family will help to prevent this happening.

2.2.12 When children are placed in foster care, parents should continue to receive practical support to maximise their chances of improving their parenting capacity.

Without this, parents will have little chance of reunification with children who have been removed from their care. Parents are likely to have strong reactions to separation from their children (particularly when it triggers feelings from previous experiences of loss). They will need help with these painful emotions in order that their reactions do not unnecessarily jeopardise their chances of reunification with their children.

Good practice example

Children's social care had been involved for some time with the Everett family. Ms Everett has learning disabilities, her partner does not. They have two children – a son aged 20 and a daughter aged 13, Rachel (who has learning disabilities). Ms Everett treated Rachel as confidante and best friend and wanted to have Rachel at home with her. Consequently, her school attendance was very poor. There were also significant concerns about a lack of hygiene, nutrition and general care.

Rachel was placed on the child protection register, removed to temporary foster care and children's social care applied to the court for a Care Order. However, the judge felt that the family hadn't been given sufficient opportunity to see if things could improve with support. Children's social care then arranged for support to be provided by a local voluntary organisation. They:

- supported the family during Rachel's contact home visits by making sure everything was in place in preparation for the visit, such as food
- supported the family when contact visits were extended to include Sunday nights and ensured that Rachel then went to school the following morning
- helped with hygiene, routines and engaging with other services
- helped both parents to access Learn Direct in their village
- arranged, through the GP, for Ms Everett to see a counsellor with whom she explored her childhood experiences and their impact on her as a mother.

Ms Everett was able to see that Rachel was a lot happier when she went to school regularly, seeing her friends and doing activities outside school such as horse-riding (which was arranged by the foster carer).

Rachel has returned home, attends school regularly and has been taken off the child protection register. She still goes horse-riding and occasionally stays overnight with the foster carer. The voluntary organisation's support worker visits once a month to check whether Ms Everett needs any more support.

2.2.13 As long as continuing parental involvement when children are placed in foster care is not considered detrimental to a child's welfare, it should be positively encouraged and promoted, and parents should be supported to be involved in their children's lives.

This involvement should encompass both contact between parents and children and the involvement of parents in the decisions affecting children's lives.

Because foster care basically provides for shared parenting, birth parent involvement is beneficial to everyone involved – child, parents, foster carers and social worker.

Vera Fahlberg (1994), *A Child's Journey through Placement*

2.2.14 Placement with extended family members should always be considered.

Support from the extended family can work well and can take the form of 'shared care' or of permanent placement. On the other hand, there are some circumstances where extended family members would not provide suitable support, and there are other circumstances where extended family members attempt to 'take over' care of children without appropriate involvement of parents. Assessments that take into account the wider context of the parents' and children's circumstances and needs will ensure that care planning is fully informed by both the possibilities and the limitations of extended family involvement.

2.2.15 Where possible, foster care placements should be made with carers who have experience and/or training in working in partnership with parents with learning disabilities.

2.2.16 Parents should be informed of the complaints procedure and it will be important that such procedures are conducted in ways which ensure that people with learning disabilities have equal access to all stages of the complaints process. This should include information in easy-to-understand formats and any support required to use the complaints procedure.

2.2.17 Local authorities should make reasonable adjustments to procedures in relation to care proceedings in order to avoid discrimination against parents with learning disabilities.

Key issues for parents with learning disabilities involved in pre-proceedings and court proceedings are their needs for accessible information, support of an independent advocate, enough time to understand what is going on, to be fully involved in any assessments and care planning, and to have the chance to learn and demonstrate improved parenting capacity.

Good practice for the courts (and for solicitors and Guardians Ad Litem) is outside the remit of this *Guidance*. However, while children's interests must be paramount, it will be important that local authorities make whatever reasonable adjustments are required to their own practices and procedures in order to give parents with learning disabilities equality of opportunity to retain the care of their children.

Moreover, in order to fulfil their disability equality duty, anticipatory action should be taken to ensure this equality of opportunity, rather than just responding to individual cases as they arise. It will be important, for example, that monitoring of timescales for assessments, care plans and care proceedings looks at whether targets are creating obstacles to making reasonable adjustments for parents with learning disabilities.

Good practice example

West Sussex produces easy read versions of its pre-proceedings letters.

Manchester writes an easy read letter from the perspective of the child, setting out the concerns and actions needed, in the voice of the child.

Some local authorities ensure that the list of local children-law-accredited solicitors they include in their pre-proceedings letter highlights those solicitors with experience of working with parents with learning disabilities.

2.2.18 Parents should have access to both emotional and practical support when the child protection process concludes with children being removed.

Parents' grief should be recognised and responded to. Such bereavement is particularly hard to bear when parents have experienced other losses in their lives (including in their own childhoods) and services should be aware of parents' vulnerability and needs for considerable support in such a situation.

Parents should be supported to avoid the situation where they conceive another child without their parenting support needs being addressed. Repeated removals of babies and young children into care can be avoided if the necessary support is provided to people with learning disabilities. It will also be important to work with health colleagues to enable people with learning disabilities to have access to family planning and other health services.

An independent advocate can help parents to access services to support mental and physical health and to address housing and benefit issues.

2.2.19, Statutory guidance from the Department for Education – Court Orders and Pre-proceedings for local authorities (2014) – provides a short section about local authorities' responsibilities after proceedings:

> The child's social worker should consider the on-going support needs of the family and any other children involved, in consultation with them. It may be necessary to provide targeted support and intervention, or refer parents to adult services, where they are experiencing particular problems. (Para 37)
>
> Once permanence is secured for the child, it is good practice for the local authority to carry out a comprehensive review of the effectiveness of its processes over the lifetime of the case, which would include the views from children/service users and other professionals involved. (Para 38)

They were all coming round my house and then when he was adopted they stopped coming and no-one talked to me about it. It was very hard.

Section 3 Good practice in commissioning

Working in partnership to deliver effective joint commissioning is the third key area involved in the joint commissioning agenda. Real partnership goes beyond the ability to negotiate with partners to get the best for your individual agency or service, and requires the desire to work across boundaries to get the best outcomes for people with learning disabilities … and their families.[18]

Good practice in supporting parents with learning disabilities depends on a commissioning strategy jointly developed and agreed between commissioners, policy makers and senior managers from adult and children's services, and encompassing health, education, housing and social care services in both the statutory and voluntary/ independent sectors.

It is important that adult and children's services take joint responsibility for commissioning services to meet the needs of parents with learning disabilities and their children. This joint responsibility will need to be taken at all four stages of commissioning:

- Identifying needs and mapping existing service provision
- Allocating resources
- Developing services
- Monitoring and reviewing.

Chapter 15 of the Care Act 2014 Care and Support Statutory Guidance addresses commissioning in detail.

3.1 Identifying needs

3.1.1 A commissioning strategy should be based on knowledge of current and likely future needs. Adult learning disability services need to have an idea of the demand for support from parents with learning disabilities. An audit of the current numbers of parents with learning disabilities and an estimate of future numbers would provide an important starting point for a commissioning strategy.

Children's social care need to know the number of children in need, and the number within the child protection system, whose parents have learning disabilities. Again, an audit of current

[18] National Commissioning Board – Commissioning Services for People with a Learning Disability – Good Practice Guidance (Nov 2017), https://ipc.brookes.ac.uk/publications/Commissioning_for_People_with_Learning_Disability.pdf.

numbers and an estimate of future numbers would provide a useful starting point for commissioning.

3.1.2 A commissioning strategy needs to be based on an audit of current service provision and the identification of the gaps in service provision. Specialist parenting services leads, teams or hubs can be key to providing this information.

> *I think the long-term impact in providing a better service to our families is to have a multi-disciplinary team in house for example. So we can align all our services to make the best use of each other's budgets and service provisions.*
>
> Special parenting services manager – Getting Things Changed project[19]

An audit of current service provision is an opportunity to establish where in the statutory and independent sector, across health, social care, housing and education, parents with learning disabilities and their children currently receive support. Such an audit could cover not only specialist services but also mainstream universal settings, such as midwifery services, health visitors, after-school clubs, etc. A lot of this information will be available already as part of the Children and Young People's Plan, Supporting People strategies, and so on.

Housing is a major issue for many families affected by parental learning disability so it will be important to include housing in audits of needs and services.

It is also helpful if commissioning strategies recognise both the role of schools and the support needed by parents if they are to promote their children's educational development. Parents have a key role to play in supporting their children's education, and there is evidence that they often experience barriers to fulfilling this role.

One method which has proved useful to commissioners in a range of contexts is to select a sample of 'cases' or placements and analyse the needs (including unmet needs), service responses and costs. This method has proved particularly useful in identifying low incidence, high-cost needs.

3.1.3 Service user perspectives should inform the identification of need.

Families affected by parental learning disability, and those who work with them, can provide valuable perspectives on existing service provision (both specialist and mainstream), unmet needs and ways of meeting such needs. It is helpful if commissioning strategies include proposals for co-producing or consulting with these groups. Consideration will have to be given to the

[19] www.bristol.ac.uk/sps/gettingthingschanged/.

resources needed to enable such consultation to take place and the time-frame for drawing up the strategy in order to take account of what is required to consult effectively.

3.2 Allocating resources – pooled budgets

3.2.1 It is good practice to have formal joint commissioning arrangements which are underpinned by formal pooling of budgets. Informal arrangements are too vulnerable to changes in personnel or changes in priorities.

3.2.2 Pooling budgets helps to promote a more integrated approach to commissioning, eligibility and care planning, and service provision.

Most importantly, pooling budgets should prevent the problem where parents with learning disabilities can fall between children's and adult services, as each attempts to defend their respective scarce resources. One such example is the frequent debate over whose responsibility it is to provide an independent advocate to support a parent with learning disabilities.

The Better Care Fund, which provides local authorities and Clinical Commissioning Groups with a shared fund to invest in agreed local priorities which support health and care and support, is a key opportunity to promote integration in provision to ensure access to, and availability of, a range of preventative care and support services in the community (Care and Support Statutory Guidance, chapter 15.12)

There are no restrictions on local authority adult and children's services pooling resources, and local authorities may also pool resources with 'relevant partners' such as District Councils under section 10 (Co-operation to improve well-being) of the Children Act 2004.

3.3 Developing services

3.3.1 The development of services should be underpinned by the principles and aims of Valuing People Now, Children Act 2004, the Care Act 2014 and the Equality Act 2010.

Valuing People committed Learning Disability Partnership Boards to "ensure that services are available to support parents with a learning disability" and set out four key principles for meeting the needs of people with learning disabilities generally. These are:

- Legal and civil rights: "People with learning disabilities have the right to … marry and have a family … with help and support to do so where necessary."
- Independence: "… the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided."
- Choice: "We believe that everyone should be able to make choices."

- Inclusion: "Inclusion means enabling people with learning disabilities to do … ordinary things, make use of mainstream services and be fully included in the local community."[20]

The Children Act 2004 placed a statutory requirement on children's services authorities to improve 'wellbeing' for all children in their area by enabling children to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- have economic wellbeing.

Children's services authorities also have a duty to reduce inequalities in wellbeing between young children in their area.

Good practice example

In one local authority, a section 75 NHS Act 2006 pooled budgets arrangement for learning disability services had been set up between the local authority and local health services, which specifically included a contribution from children's services to help ensure a focus on the family as a whole.

Source: Getting Things Changed project[21]

Local authorities fulfil a range of different functions that have an impact on the health and wellbeing of individuals, in addition to their care and support responsibilities (e.g. children's services, housing, public health).

They have a duty under section 6(4) of the Care Act 2014 to ensure that, in addition to ensuring co-operation between the local authority and its external partners, there is internal co-operation between the different local authority officers and professionals who provide these services. Local authorities must make arrangements to ensure co-operation between its officers responsible for adult care and support, housing, public health and children's services, and should also consider how such arrangements may also be applied to other relevant local authority responsibilities such as education, planning and transport.[22]

---

[20] Source: Department of Health (2001), p.23.

[21] www.bristol.ac.uk/sps/gettingthingschanged/.

[22] Care and Support Statutory Guidance, chapter 15.23.

3.3.2 Good practice in commissioning considers both the role of mainstream services and the development of a range of specialist services.

Local services will know from their own experiences, and we also know from the research summarised in Appendix A, that a range of service responses are likely to be needed to meet the needs of families affected by parental learning disability. Some of these responses concern the development of particular expertise or provision within existing mainstream or social care services; others concern the development of specialist services. They include:

- expertise in working with parents with learning disabilities amongst midwifery and health visiting services
- liaison roles between different services, e.g. between adult and children's social care
- expertise in assessments of parents with learning disabilities where there are concerns about children's welfare
- parent support services – both specialist and mainstream services
- parenting courses, parents' groups – both specialist and mainstream services
- independent advocacy services
- direct payments support services
- adult placement services for parents with learning disabilities and their children
- foster carers experienced and/or trained in working in partnership with parents with learning disabilities
- housing and housing-related support
- accessible information and availability of communication resources
- counselling and therapeutic services, and self-advocacy/self-help groups.

Good practice example

Specialist services were operating in the three local authorities that participated in the research. The special parenting services were seen as a resource for practitioners across the local authority. Professionals in these teams provided leadership at strategic level and an on-going resource for local professionals by way of advice, consultancy and training.

The specialist services appeared to be working in two ways:

Consultation model – where parental learning disability specialists were called in to support or advise other practitioners such as children's services social workers, health visitors, school nurses.

Hub model – in which specialists at the centre co-ordinated all other practitioners' involvement with the family.

Local authorities resourced specialists working with parents with learning disabilities, whether they worked as individuals, in teams or in hubs, who could gather and share expertise, drive activity, set the appropriate speed and direction of family work and link with every practitioner involved in a case, to ensure a holistic, family-focused approach.

It was recognised that parents might require long-term or recurrent support as learning disabilities are lifelong and the families' needs and circumstances would change over time.

Source: Getting Things Changed project[23]

3.3.3 Some analysis of the economic case for investing in early support and independent advocacy was carried out by the Personal Social Services Research Unit (PSSRU) in its *Report on the economic case for early and personalised support for parents with learning difficulties* (Bauer, 2015)[24] and *Investing in advocacy for parents with learning disabilities: what is the economic argument?* (Bauer et al, 2015)[25]

3.3.4 Service user perspectives should inform the development of both mainstream and specialist services, as recommended throughout the Care Act 2014 Care and Support Statutory Guidance.

Both parents and children usually have clear ideas about what would meet their needs and it is important that these messages inform any commissioning strategy. Current service providers, including specialist services in the independent sector, also have a valuable perspective.

Commissioning strategies should include proposals for consulting with these groups. Resources may need to be allocated to enable such consultation to take place and the timeframe for drawing up the strategy should take account of what is required to consult effectively.

3.3.5 Training for both children's and adult services on working with parents with learning disabilities.

Both children's and adult workers will need specific training in order to respond appropriately to the needs of families affected by parental learning disability. Child protection training strategies should include adult learning disability services. Those responsible for commissioning training will also need to ensure that specific training is available on assessing and meeting the needs of parents with learning disabilities for all workers who come into contact with them and their families – including, for example, mainstream services such as midwifery and health visiting.

[23] www.bristol.ac.uk/sps/gettingthingschanged/.
[24] http://eprints.lse.ac.uk/64778/1/__lse.ac.uk_storage_LIBRARY_Secondary_libfile_shared_repository_Content_PSSRU_Discussion%20Papers_DP2907.pdf.
[25] https://www.pssru.ac.uk/publications/pub-4612/.

It is often helpful if parents with learning disabilities are involved in delivering such training. The Resources section of this *Good practice guidance* provides some information about both training materials and organisations that can provide training.

3.4 Monitoring and reviewing the effectiveness of service responses

3.4.1 Services to parents with learning disabilities and their children should be monitored and reviewed using frameworks and criteria such as those operated by Learning Disability Partnership Boards and children's services.

However, it will be important to gather such data in a way which enables the outcomes for parents with learning disabilities and their children to be distinguished from other service user groups. This is the kind of exercise required as part of the public sector equality duty, so that local authorities can assess whether they are fulfilling their duty to advance equal access and equal opportunities for disabled people.

3.4.2 Statistical data on comparative outcomes can be supplemented by qualitative data in order to fully understand the reasons for any differences in outcomes.

For example, some organisations have expressed concern that the children of parents with learning disabilities, who enter the child protection process, are more likely to be permanently removed from their parents than the children of parents who do not have a learning disability. If monitoring of service provision in a locality reveals such a pattern, it is advisable to use qualitative methods such as case audits to understand why this is, and the implications for service provision.

3.4.3 Monitoring and reviewing of services should include the perspectives of service users.

As in all stages of the commissioning process, the perspectives of parents with learning disabilities and their children will be key to any evaluation of how services are doing in meeting their needs. The involvement of parents with learning disabilities is also an important part of fulfilling the public sector equality duty, as required by the Equality Act 2010 (see Appendix B).

Appendix A What do we know about the needs and circumstances of parents with learning disabilities?

Research can tell us about the likely needs, or risk of negative outcomes, associated with a range of factors. It cannot tell us what is true for a particular parent, child or family.

Research can therefore be useful if it alerts practitioners to the factors that they should be looking out for. However, research should not be used to bolster an assumption that a particular family's characteristics and/or situation will inevitably lead to a negative outcome.

Similarly, research can tell us what type of intervention helps most parents and children who have a particular set of needs. It cannot tell us what will definitely help this particular parent or their children. The research discussed below indicates that support for parents and their children needs to be relationship-based and tailored to the individual needs and context.

An increasing body of evidence exists about the types of support which help promote positive improvements for families affected by parental learning disability. Unfortunately, there is also evidence that many parents with learning disabilities do not receive such support. This Appendix focuses on research that can support improved outcomes for families.

What do we mean by 'learning disability'?

Learning disability can be defined as a disability that includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with
- a reduced ability to cope independently (impaired social functioning); and which
- started before adulthood, with a lasting effect on development.[26]

It is important to recognise the following:

- A particular level of IQ cannot be taken as the only defining characteristic of learning disability.
- Individuals can have different ability levels across the different components of IQ and other tests.
- While 2.2% of the population is recognised as having a learning disability (varying from 'mild' to 'profound'), another 6.7% fall within an IQ range of 70–80 (Weschler Adult Intelligence Scale – Revised, 1997).

[26] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf.

- It can therefore be difficult to clearly demarcate those parents who have learning disabilities and those who do not.[27]

In the context of parenting, it is more helpful to identify support needs associated with the impact of the parent's learning disability, rather than to take a rigid approach to the definition of learning disability.

Parents with learning disabilities may have support needs associated with their impairment, but they may also have support needs associated with other factors such as poor health, inadequate housing or stigma related to having a learning disability – see below.

Learning disabilities or learning difficulties?

Many people who have the label 'learning disability' have said they prefer to be called 'people with learning difficulties'. They use this term to mean 'people who since they were a child had a real difficulty in learning many things. We do not mean people who just have a specific difficulty in learning, for example, people who only have difficulty with reading which is sometimes called dyslexia' (Emerson et al., 2005).

One of the objections that people have to the term 'learning disability' is that it can be taken to mean that they are not able to learn. Such an assumption has particular implications for parents who may be facing a situation of having to prove that they can look after their children.

On the other hand, the term 'learning disabilities' is used within the statutory framework for social care support while the term 'learning difficulties' is used within the special educational needs statutory framework, and the two definitions are not the same. Indeed, it is clear that when people self-define themselves as 'people with learning difficulties' they mean people who, within the statutory framework, would be referred to as 'people with learning disabilities'.

Practitioners will want to be sensitive to how people define and describe themselves and to use language that parents are comfortable with, in their contact with them.

The principles of this *Good practice guidance* are equally applicable to working with parents with a milder impairment, such as the 6.7% of adults falling within an IQ range of 70–80 (Weschler Adult Intelligence Scale – Revised, 1997), who are in need of parenting support but often not able to access support from the learning disability team.

Numbers of parents involved with services

There are no definitive figures regarding numbers of parents with learning disabilities. Reasons for this include inconsistencies in assessment procedures and the fact that some adults with mild

[27] This is a summary of the useful discussion in McGaw and Newman, 2005, pp. 8–14. While these figures are old, it is still recognised that around 2% of the population have a learning disability.

learning disabilities may only come to the attention of statutory services when they have a child and need support. Before this, they may not have needed or been eligible for statutory services. Parents with undiagnosed, mild learning disabilities who are in need of support with their parenting will not show up in official figures.

Hatton et al. (2016: 04) estimated that in England in 2015 there were over 1.08 million people with learning disabilities, including 930,400 adults. As indicated, this is not an exact figure, but was arrived at by combining data from a range of sources including "information collected by government departments on the presence of learning disabilities among people using services, overall population predictions for England and the results of epidemiological research" (Hatton et al., 2016: 04). It is estimated, using data from the *Oxford Record Linkage Study* (ORLS) in South East England, that 0.9 per 1,000 births are to women with what were referred to as 'intellectual disabilities' (Goldacre et al., 2015).

It is not known how many parents with learning disabilities in England are involved with child protection services, as no records are kept identifying whether or not a parent has this diagnosis. It has been argued that "there is a propensity for parents with learning disabilities to be over-represented in care proceedings" (Stewart et al., 2016: 21 see also Burch et al., 2019; Cox, Kroese & Evans, 2015; Hewitt, 2007). Masson et al. (2008) found that 12.5% of the parents involved in care proceedings in England and Wales had 'learning difficulties' (this term was not specifically defined).

Slayter and Jensen's (2019) study, using US national-level data, found that in 1,013,464 cases of suspected child maltreatment in 2013, 0.8% (7831) of the cases where maltreatment was suspected involved parents with intellectual disabilities[28] and of these cases 31.3% were substantiated.

This rate of nearly one third of cases being substantiated was in comparison to 20.8% of the cases of parents who did not have a learning disability. Over a third (36.7%) of the substantiated cases involving parents with learning disabilities involved at least one child with previous involvement with the child protection system.

LaLiberte, Piescher, Mickelson, & Lee, (2017) also found, using a state-wide data set, a pattern of increased disparity among parents with intellectual disability along three child protection service decision points: investigation, out of home placement and termination of parental rights.

A Canadian study in 2003, found that parental cognitive impairment (defined as parents with intellectual disabilities and borderline intellectual functioning) was noted in 10.1% of sampled cases that were opened for child maltreatment investigation and in 27.3% of sampled cases that resulted in child welfare court application (similar to care proceedings) (McConnell, Feldman, Aunos & Prasad, 2011).

[28] 'Intellectual disabilities' is the term used in the study and found commonly in European and North American literature.

Previously, Booth, Booth and McConnell (2005) found that one-sixth of children subject to care proceedings had at least one parent with a 'learning disability', this figure rising to almost a quarter if parents with 'borderline (mild) learning disabilities' were included (Full Scale IQ 70–79). These rates of involvement with child protection services/care proceedings are disproportionate in relation to the small number of parents with a learning disability.

Again, due to a lack of consistent and appropriate recording, it is not known how many parents have their children removed from their care.

In 2008, analysis of case files across ten local authority areas in England found that in less than a fifth of cases involving parents with learning disabilities the children were removed, and most were fostered rather than adopted, and there "was no evidence to suggest that parental learning disability in itself was the reason children were removed" (Cleaver and Nicholson, 2008).

Three studies about parents with learning disabilities suggest that, once involved in the child protection system, 40% of the children of parents with intellectual disability were no longer living with their biological parents (Aunos, Goupil, & Feldman, 2004; Booth and Booth, 2004a; Booth & Booth, 2004b; Llewellyn and Hindmarsh, 2015).

Research in Wales in 2019, found that children whose parents had learning disabilities were twice as likely to be removed from their parents than be supported to remain at home (Hodges and Brigstow, 2019).

Learning disability and its relationship with neglect and abuse.

IQ is not a good indicator of parenting capacity. Tymchuck, 1992 (p. 168) clearly stated that "… IQ by itself, is not a predictor either of the occurrence or of the non-occurrence of purposeful child abuse …". There is also no clear relationship between IQ and parenting ability, unless the IQ is less than 60 (Tymchuk 1992; McGaw and Newman, 2005). McGaw et al. (2010) looked at 101 parents in contact with a learning disability parenting service and confirmed that IQ of the main parent-carer was not correlated with risk of child protection concern.

On the other hand, as discussed below, parental childhood trauma, parent's physical disability and having a child with special educational needs were associated with high risk of child protection concerns. In addition, having a partner with a higher IQ than the main parent-carer was also associated with a higher risk of significant harm or care proceedings.

A cognitive impairment may mean that a parent has difficulty with reading and writing, remembering details such as the times of appointments, and understanding abstract concepts such as time. They may also struggle with decision-making and problem-solving, organising routines, and keeping their children safe. These types of difficulties can result in inadequate levels of childcare.

When the children of parent/s with learning disabilities are on a care plan, it is usually under the neglect or emotional abuse categories. This is "neglect by omission" which Cleaver & Nicholson,

(2008) link to a lack of parental education combined with the unavailability of supportive services (McConnell et al., 2011a, 2011b; McConnell & Llewellyn, 2002; Tymnchuck, 1992).

Most parents with learning disabilities in contact with social care experience a range of difficulties.

When parents with learning disabilities come into contact with child protection services, they often have particularly high levels of need and typically present as complex 'cases' where it can be difficult to disentangle the competing concerns (Cleaver and Nicholson 2008; Stewart et al., 2016). Burch et al. (2019), reporting on child protection cases in Wales, found:

> parental or family characteristics (that can also present risks) including parental substance misuse, domestic abuse, and/or parental mental health problems; poor home conditions; or parental vulnerability to abusive adults in the community. In many cases, the child of concern to services already has older siblings or half siblings in care (p. 5).

In addition to their learning disability, parents may also be experiencing a range of disadvantages, such as having mental health support needs, being unemployed and reliant on benefits, living with domestic violence and abuse, or having poor housing in difficult neighbourhoods. (Cleaver and Nicholson 2008; Darbyshire and Stenfert Kroese, 2012; Redley 2009; SCIE, 2005).

Parents with learning disabilities may also face all of the stigma and possible harassment that any person with a learning disability commonly faces but may also encounter very negative social attitudes and assumptions about their capacity to parent well (Cooke 2005, Cox, et al., 2015; CHANGE 2005). Indeed, there is often a presumption that they cannot or should not be allowed to parent at all.

Domestic violence, financial or sexual exploitation, can be major problems for parents with learning disabilities and their children. McGaw, Shaw & Beckley (2007) found that three-quarters of the parents, involved with a specialist service for parents with learning disabilities, reported abuse and neglect in their own childhoods.

Parents often do not have a supportive social network or the help they need to develop their parenting knowledge and skills (Collings, Grace and Llewellyn, 2017; Darbyshire and Stenfert Kroese, 2012; Emerson and Brigham, 2013; Tarleton, Ward and Howarth, 2006). For instance, if parents struggle with literacy, they will not be able to read most of the literature available on parenting – and they may have missed out on the experience of babysitting young children or being in situations where they have had the chance to learn about and/or take any responsibility for their care, before finding themselves in the position of being the primary carer for their own baby.

Pregnant women with learning disabilities have also been recognised as a vulnerable group since a higher proportion of pregnant women with learning difficulties are teenagers, obese, single and smokers (Goldacre et al., 2015; Hoglund, Lindgren & Larsson, 2012b). They have also been found to be at a higher risk of pre-term birth, birth by caesarean section and increased likelihood of

having smaller babies (Hoglund, Lindgren & Larsson, 2012a). Mothers may be fearful of attending antenatal classes or may struggle with understanding what is happening, so will need tailored support.

Maltreatment risk factors and service response.

As noted above, parents with learning disabilities often come into contact with services due to concerns regarding neglect by omission, i.e. parents do not know how to ensure the well-being of their children; they also face a wide range of factors that impact on their ability to parent well such as poverty, mental health needs, substance abuse issues, domestic violence and level of social support.

These factors are widely recognised as risk factors for maltreatment generally (Slayter and Jensen, 2019). Drawing on national-level data from the United States child protection system in 2013, Slayter and Jensen (2019) conclude that, as parents with learning disabilities face all these challenges in their environments, the 'presence of parental intellectual disability may be more of a risk indicator as opposed to a factor for maltreatment' (p. 297).

Slayter and Jensen also highlight that parents are likely to have all of the risk factors, but at slightly different rates to parents involved in substantiated cases who do not have learning disabilities. Cases involving parents with learning disabilities are slightly more likely to involve psychological or emotional abuse but less likely to involve sexual abuse.

Risk factor	**Parents with learning disability %**	**Parents without learning disability %**
Physical abuse	17.8	17.5
Neglect/deprivation of necessities	65.9	66.8
Medical neglect	1.6	1.7
Sexual abuse	5.6	10.0
Psychological or emotional maltreatment	5.7	4.1
Other	2.7	0.6

This paper also noted that there were differences in the support offered to parents with and without learning disabilities. Parents with learning disabilities were:

- six times less likely to receive a referral for emotional support
- three times more likely not to be referred for support with issues with alcohol
- three times less likely to get help with substance abuse
- two times more likely not to be referred for support with housing.

The study also found that only 8.1% of the cases received 'family preservation services' compared to 21.9% of parents without learning disabilities whose cases were equally or less concerning.

The authors call for preventative services to be provided to parents to prevent and ameliorate the higher rates of emotional and psychological abuse reported. They called for the provision of 'parent supports' (Lightfoot and La Liberte, 2011), similar to 'parenting with support' (Tarleton et al., 2006), and the involvement of specialist workers. However, they also note that when a parent has a learning disability, this may shift the case work away from the parent's behaviour with the child to focus on the parent's diagnoses.

Slayter and Jensen's conclusions appear to show that parents with learning disabilities receive a different response to their support needs. Other studies have also shown that parents with learning disabilities can experience discrimination when involved with child protection (Cleaver and Nicholson, 2008; Llewellyn, McConnell, & Ferronato, 2003; Swain & Cameron, 2003).

Cox et al. (2015) reported that caseworkers had unrealistically high expectations of what constituted 'good enough parenting' by parents with learning disabilities and that parents could be set up to fail. Sigurjonsdottir and Rice (2018) also discuss prejudicial attitudes in Iceland, within the child protection system. These findings reflect parents' comments that they are not expected to parent well and can be expected to meet higher standards of parenting.

Issues to be aware of

Social care involvement

Almost all the information we have about parents with learning disabilities concerns those who are in contact with social care and mostly mothers. We know very little about the needs and experiences of families where at least one parent has learning disabilities but who are not in contact with social care.

Fathers

We currently know very little about the experiences of fathers with learning disabilities, other than exploratory research undertaken by Dugdale and Symonds (2018). Dugdale and Symonds found that fathers felt:

- responsible for their children and wanted to be fully involved in raising their children
- excluded by services which tend to focus on the mother
- pressure from constant assessments and that they had more to prove during assessments
- isolated – it was difficult for fathers to be in contact with each other

- in need of support with paperwork and bills etc.

(See http://www.bristol.ac.uk/sps/wtpn/resources/ for an audio play and video by fathers with learning disabilities for fathers with learning disabilities.)

Ethnicity

Much of the research discussed in this Appendix focuses on white mothers with learning disabilities who are involved in the child protection system. There is little published research about parents with learning disabilities in a minority culture.

Two papers, from authors in England, indicate that Bangladeshi parents often live with their families, which can result in their exclusion from the parenting role as this is taken on by the grandparents (O'Hara and Martin, 2003). More recently, Durling, Chinn and Scior (2018) also working with Bangladeshi parents in London, found that learning disability was a difficult concept for families to understand; the difficulties were seen as part of 'normal' life, and adults with learning disabilities were supported to marry and have children. Parenting was seen as a shared task in which the parent/s with learning disabilities played a role. Mothers with learning disabilities were therefore more likely to retain custody as they were in a supportive context.

Outcomes for children

Research evidence suggests that outcomes for children of parents with learning disabilities may be mixed, especially if parents are not provided with support that can help ensure the well-being of their children.

Collings and Llewellyn's (2012) literature review found that poorer outcomes for children of parents with intellectual disability were linked to poverty and poor social environments associated with the parents' intellectual disability, rather than the parents' disability itself. However, Emerson and Brigham's (2014) UK study, adjusted for between-group differences related to low socio-economic position, showed parental learning disability was associated with an increased risk of child developmental delay and speech and language problems, but not of child behaviour problems or frequent accidents or injuries.

Hindmarsh et al.'s (2017) secondary analysis of data from waves 2–4 of the UK Millennium Cohort Study also found that children face a heightened risk of poor social-emotional well-being (at ages three and five) and peer exclusion (by self-report) at age seven, while Wickstrom et al. (2017) found that at seven years old, children of parents with intellectual disabilities in Sweden were at increased risk of injuries, violence and child abuse.

Adult children of parents with learning disabilities discuss experiencing stigma, bullying and ostracism associated with their parents' disability (Booth & Booth 1998; O'Neill 2011; Ronai 1997), while Lindblad et al. (2013) also note that children may experience later difficulties with relationships.

Children's experiences and the type of support they need from others

There is a growing knowledge base regarding the experiences of children of parents with learning disabilities. Wołowicz-Ruszkowska and McConnell (2017, p. 482) discuss children experiencing a 'different, yet ordinary' life in which their parents were generally loving and supportive. Collings, Llewellyn and Grace (2017) add that children do not see their social worlds as restricted but as influenced, like all children, by a wide variety of things rather than just their parent's(s') learning disability; they also note (again like all children) that they benefit from stable and supportive environments.

Recent research has, however, indicated that the children of parents with learning disabilities, like their parents, may have insufficient social support (Booth and Booth, 2007; Faureholm, 2010; O'Neill, 2010; Ronai, 1997) and support from key adults who are interested in the child has also been increasingly recognised as beneficial for these children.

A review of the academic and grey literature by Gudkova, Hedlund and Midjo (2019) drew together current understanding of how children need to be supported. It highlighted the importance of positive relationships between the child and supporter who provides a secure, interested relationship, based on unconditional acceptance. The supporter should provide ongoing support that is responsive to the child's interests and social needs. The supporter was also recognised as needing to have a positive relationship with the child's parent and that the support is particularly important if the family is not provided with any 'formal' support from services.

This support can be from siblings, family, a family friend, a worker from a support service or a teacher but it should be consistent, long-term and respond to the child's individual needs. The person must also have a positive relationship with the child's parent (Collings, Grace and Llewellyn, 2017; Collings, Llewellyn and Grace, 2017; Faureholm, 2010; Gudkova, Hedlund and Midjo, 2019; Lindblad, 2013; Weiber et al., 2014).

This type of individually tailored support might include the supporter driving children to school and football practice and helping children to build social skills and social networks, or protection from 'troublesome peers' (Collings, Grace and Llewelyn, 2017).

Collins, Llewellyn and Grace (2017) point out there are also examples of relationships with children that are not beneficial, such as teachers not noticing bullying and children being 'invisible' to support workers. It therefore appears that it is the quality of the relationship that is important (see the section on informal support for parents below) and the length of time that the relationship continues.

These recent findings accord with findings from the seminal work by Booth and Booth (1997). This study interviewed 30 adult children of parents with learning disabilities about their experiences of childhood and adulthood. These were children who remained with their families and no comparison was made with children taken into alternative care. Four themes emerged from the interviews:

- More attention needs to be paid to the protective factors which promote resilience amongst children and which "shield them from the potentially harmful effects of parenting deficits".
- Parental "competence may more properly be seen as a feature of parents' social networks rather than as an individual attribute". Outcomes for children are not just a function of the skills or attributes of their parents but also of the presence and extent of the skills of their extended family, neighbourhoods and communities. There is therefore a need to pay attention not just to parent education and training but also to promoting and nurturing other forms of support.
- For most of the adult children in the study, their relationship with their mother and/or father was extremely important to them.
- Experiences of social exclusion ran through the children's childhoods and, for those with learning disabilities in particular, continued into adulthood. These experiences included bullying and harassment at school and in their local neighbourhoods, poverty and unemployment, and experiences of not being listened to by people in authority (Booth and Booth, 1997, pp. 37–38).

A group of children of parents with learning disabilities (aged between 13 and 18), was consulted as part of drawing up the original 2007 *Good practice guidance*. Their views are still pertinent today. They too identified bullying – at school and in their neighbourhood – as a major issue for them. The bullying included physical violence.

> *The police said if they get so many warnings they would prosecute but they didn't prosecute them and I think they should have. I don't understand why the police didn't do anything about it.*
>
> *What helps is other people helping you be strong.*
>
> *I just ran away from the bullying. The school didn't do anything.*

The young people were asked about the help their families received from social care. They said that having people coming into the home to help their parents can be good because they help with tidying up and with decorating, and they also help with forms to get benefits.

> *The house looks a lot better. Did that mean a lot to you? Yes, because I can have my boyfriend to visit. Was it hard having a stranger coming in? No not really, I accepted the fact that they came in.*

However, they also said that having people coming into their home can feel like an invasion of their privacy, there are often too many different people coming in, and their parents find it stressful.

> *I used to go out when the helper came in. I just didn't want to be there. There were so many different ones. It just felt they were invading our privacy.*

They don't explain things properly and so you don't understand what they want. … My mum gets stressed because she feels she's being pushed.

The young people also felt very strongly that professionals should listen to children more.

They should listen to us, instead of just taking the adults' point of view.

They should pay more attention to children.

A child's voice can make a lot of difference.

When asked what could be done better, the young people said that their families needed more help with filling forms and claiming benefits, and help with reading instructions such as recipes for cooking. They also felt that it generally took too long to get help and that their parents found it stressful when they were pushed to do things too quickly.

The Commission for Social Care Inspection consulted in 2006 with children on the child protection register and reported that they felt that "many parents get too little help, too late". The young people "had strong views about the importance of helping parents, both in their own right and in relation to children's needs. They recognised that parents need clear messages about what needs to change, and help to do so" (Commission for Social Care Inspection, 2006, p. 44).

My mum and dad both have learning disabilities as does my younger brother … Information from school comes through the internet. My mum and dad can't use the computer and wouldn't really be able to read it anyway. If my teachers had really understood what my life is like, I think I would have had better support and achieved more. Katie (2018)

These comments confirm the need for supporters to notice the child and develop a relationship with them, as discussed in the recent literature above.

Informal and family support for parents

Parents with learning disabilities often have smaller support networks and fewer friends (Collings, Grace and Llewellyn, 2017) while Mayes (2008) found the mothers actively negotiated their own social support networks. Social support and stress are negatively correlated amongst mothers with learning disabilities, suggesting that the social support may buffer the adverse effects of stress (Feldman et al., 2002). Kroese, et al. (2002) also found that the larger, the more recent and the more helpful the support network reported by mothers with learning disabilities, the better their psychological well-being and the greater the likelihood of positive parenting experiences.

A recent inclusive study in Australia, by Strnadova et al. (2019), which included a parent researcher, found that support networks included partners, family members and support workers, as well as people from parenting/religious groups. This support provided a shared social identity, exchange of practical information and shared problem-solving, as well enabling parents to grow and be empowered together (see discussion re parents' groups below).

The support shared included emotional and practical support, child-minding and domestic help, as well as financial support. In this study, there appeared to be a blurring of informal support from family, friends and peers with support from workers from services. The quality of the relationship appears, as discussed in the section on professional support below, more important than the 'role' of the supportive person.

This research also noted, as did Tarleton et al. (2006), that parents often do not feel at home in mainstream parenting groups; this is most likely because mothers with learning disabilities feel different from the majority of mothers present.

The role of the extended family is particularly important for parents with learning disabilities (Tarleton et al., 2006). In the study above, about half of the mothers interviewed had support from family members (Strnadova et al., 2019).

Emerson et al.'s (2005) survey of people with learning disabilities in England found that those who had children were more likely to still be living with their children if they were also living with other relatives. This was particularly the case for mothers – nine out of ten mothers living with other relatives still had their children with them, compared to only four out of ten who lived in their own households. McGaw and Newman also concluded that "the importance of family ties should be recognised and no actions taken that damage such ties" (McGaw and Newman, 2005, p. 59).

Sometimes, family support may not beneficial. There are some situations where the behaviour of family members adds to the risk for children, or where they 'take over' the role and tasks of parenting in ways which are detrimental to the parent/child relationship (Gur and Stein, 2019; Tarleton et al., 2006).

Extended family members may provide an alternative to formal foster care. While 'kinship care' is associated with greater stability for the children concerned and better continuity in terms of family and cultural issues than foster care, it can be extremely difficult for the parents and detrimental to their relationship with their own parents (the child's grandparents) or other family member caring for their children (Strnadova, et al., 2019).

There is also evidence that kinship carers are likely to experience greater economic difficulties than non-kin foster carers.

Three in four of kinship carers said becoming a kinship carer has caused them financial hardship (Family Rights Group (FRG), 2019). Kinship carers have often had to make significant financial and personal sacrifices to take on the child/ren, and although the child/ren does well in their care, this can be at the expense of kinship carers' own health, finances and even relationships (FRG 2019). This must be recognised by Adult and Children's services and the relevant support provided.

How should professionals work with parents with learning disabilities and their children?

International research has shown that with timely, suitable and tailored ongoing support, parents with learning disabilities can look after their children appropriately (IASSID SIRG, 2008; McGaw & Newman, 2005; Tarleton, Ward & Howarth, 2006).

The seminal work by McGaw and Newman (2005) was clear that to enable "competent parenting, an adequate structure of professional and informal support" is required (p. 24) and that "supporting families may require a combination of skilled support during crucial child developmental periods, more 'low-level' but reliable support for lengthier periods, and commitment to the family" (p. ix).

The support, interventions and teaching methods all need to be tailored to the parents' and their children's particular situation and learning requirements. McGaw and Newman highlight that parenting support which is suitable for most parents is unlikely to be delivered in a way which is right for parents with learning disabilities. It needs to be tailored to their individual needs.

The fundamental principles for providing support and interventions for families, established in McGaw and Newman's work (p. 58) still underpin positive practice with parents:

- Interventions should build on parents' strengths as well as address their vulnerabilities.
- Interventions should be based on performance rather than knowledge and should incorporate modelling, practice, feedback and praise.
- Tangible rewards may promote attendance at programmes, rapid acquisition of skills and short-term commitment.
- Intensive service engagement is more effective than intermittent service engagement.
- Programmes should be adapted to the actual environment in which the skills are needed, in order to enable parents to generalise their learning.
- Teaching should be in the home if possible and, if not, in as home-like an environment as possible.
- Factors in the family's environment that promote children's resilience should be identified and enhanced.
- The importance of family ties (for most – though not all – parents and their children) should be recognised and no actions taken that damage such ties.
- Interventions should increase the family's experience of social inclusion rather than cause or contribute to their social exclusion.

Similarly, Burch's (2019) recommendations (p. 45) suggest that there is a need to:

- encourage and incentivise the provision of early support to parents who may have a learning disability/difficulty and who are known to be vulnerable, for example, because of adverse childhood experiences

- promote more consistent provision of well-tailored support services to meet the needs of parents with learning disability/difficulty, whether support is provided in the parent's own home or in a parent and baby placement
- promote more consistent provision of support for adults with learning disability/difficulty immediately after a child has been removed from their care, with a view to helping them to address the issues that have had an impact on their ability to parent effectively and/or to care effectively for themselves.

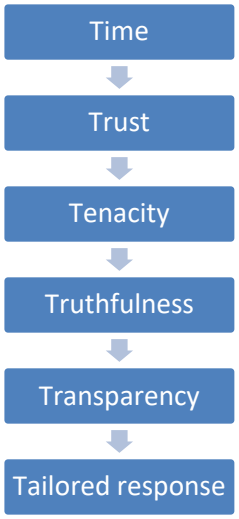
These (Welsh) recommendations also include the need for a national definition of learning disability to aid identification of parents, easy-to-read information for parents, national guidance and training for professionals, and protocols between adult's and children's services regarding working together to support parents.

Tarleton and Porter's (2012) evaluation of a specialist parenting service that provided support to parents in line with the 2007 *Good practice guidance* found that providing ongoing individually tailored support to parents improved the outcomes for the children.

Research by Tarleton et al. (2018) focused on services providing specialist support for parents with learning disabilities and developed composite case studies showing how proactive, individually tailored support could be provided by multi-agency teams.

Tarleton et al. (2018) also developed the Six 'T's practice framework as a way of explaining how positive, supportive relationships with parents could be developed by professionals. In light of the themes within the literature (above) regarding supporting children, the Six 'T's practice framework could easily be adapted to support relationship-based practice with children too.

The Six 'T's practice framework



Time: extra time is needed to get to know parents and communicate with them appropriately – in accessible ways. Parents may need more time than others to take on board information/new

skills/knowledge. Parents may need support 'through time', i.e. ongoing support in the long term or recurrent periods of support, perhaps across the span of childhood.

Trust: parents and professionals need to be able to trust each other for the support to be effective; time is needed to develop this trust.

Tenacity: professionals 'sticking with' parents over the longer term, as necessary. This may include professionals working on issues with parents over a period of time or keeping in contact so that they can come back and teach new skills as required or help a parent to refresh their confidence/competence in particular situations.

Truthfulness: professionals need to be honest with parents in relation to both strengths and difficulties. They need to be truthful about the concerns they may have for an existing child or an unborn baby's welfare and convey these concerns in terms that the parent understands. And truthfulness needs to be a two-way street: practitioners need to be confident that parents will be honest with them, for example, if they do not think things are going well with their child/ren. Again, that capacity for truthfulness depends on developing the kind of trusting relationship that can be built through time.

Transparency: professionals and parents need to be really clear about what is happening and what needs to be done when and by whom, from first referral onwards. For example, midwives need to be clear with mothers why they are involving child protection or the learning disability team.

Taking all these into account results in a **Tailored response**: understanding and working with parents in a way that works for them. Good communication is key. This response is often best provided by a multi-agency team with good coordination and leadership.

Three case studies showing how this individually tailored support was provided by multi-agency teams, can be found in Tarleton et al. (2018). WTPN (2016) and this update also provide detailed examples of positive individualised support for parents.

Multi-agency working has been recognised as central to providing co-ordinated support for parents

Coordinated, multi-agency working is regarded as vital to providing appropriate support for parents with learning disabilities (Aunos & Pacheco, 2013; SCIE, 2006; Tarleton et al., 2006). Practical ways of supporting a consistent approach between practitioners have been found to include the following:

- Use of a keyworker system to coordinate support to parents
- Sharing of information between workers with parents' consent
- Common goals, including clarity and agreement on what is required of the particular family to ensure positive outcomes for the children
- Honesty, openness and ongoing communication between all workers involved

- Understanding of individual professional roles and their boundaries
- Shared goals and attitudes developed within the team through joint training
- Creativity in finding appropriate solutions
- Training in understanding parents with learning disabilities, for workers whose experience is in protecting children
- Training and support in child protection, for workers whose experience is in supporting adults with learning disabilities.

The development of joint protocols and care pathways between all the services involved in working with parents with learning disabilities is advised. These should discuss eligibility and referrals; roles, responsibilities and accountabilities; communication; and joint training and development (SCIE 2006).

Social Care Institute for Excellence (2006) undertook a survey of research literature and an examination of good practice in multi-agency working concerning parents who have additional support needs (including parents with learning disabilities). It concluded that the following measures are required:

- Collective ownership (across adult and children's services, and across health, social care, housing and the non-statutory sector) of the need to provide early support
- Financial structures which make transparent the benefits of providing support in time to prevent higher levels of need arising
- Clear procedures for appropriate referrals at the point of first contact
- Positive action to overcome parents' potential distrust of, and disengagement with, services
- Recognition that adult services should have a lead role in responding to parental support needs
- Recognition that housing needs can be a significant barrier to parenting capacity, and that disabled parents may need assistance in supporting their children's education
- Recognition of adult services' continuing role of supporting parents when children's services carry out their responsibilities under Section 47 of the Children Act 1989.

Similarly, Aunos, Proctor and Moxness (2010), found that positive multi-agency practice in supporting parents was developed by:

- establishing clear guidelines and internal policies that support the self-determination of persons with intellectual disabilities and promote a positive approach and timely delivery of services to parents
- building partnerships with all organisations involved
- enhancing collaboration with natural/informal networks
- involving staff in training, continuing education and supervision

- appointing a case worker (key worker) who assesses the support needs and plans appropriate services.

What type of support is known to have good outcomes?

Individually tailored support may include a wide variety of different types of interventions and parent training.

Independent advocacy

Advocacy for parents with learning disabilities has been recognised as a key element of best practice with parents involved with child protection proceedings (McGhee & Hunter, 2011; Tarleton, 2013; and Collings et al., 2018) and that an advocate is a 'bridge' between parents and professionals. The involvement of an advocate reduces the power imbalance between professionals and parents and enables parents to engage more positively with the concerns for their children (rather than in anger or through fear and frustration).

The advocate provides the parent with support to understand the child protection process and the concerns for their child/ren's welfare and enables the parent to contribute to the process by putting forward their views (Booth & Booth, 1998; CHANGE 2005; Collings et al., 2018; Tarleton et al., 2006; Tarleton, 2013). This is often achieved through:

- supporting the parents in understanding reports, often by making information accessible
- being a go-between, improving links between families and services
- supporting parents to think about their position/response in relation to the concerns for their child/ren's welfare
- accompanying parents to meetings and providing ongoing emotional support
- being a sounding board for parents and supporting them to address the environmental disadvantages they experience, such as inadequate housing.

Good advocates have been recognised as having a good understanding of both children and adult services and as being able to explain both to the parents. They work to standards relevant to advocacy with adults with learning disabilities, as well as those relating to child protection (Lindley & Richards, 2002).

Tarleton (2013) showed how an advocate could be of benefit to the parent with learning disabilities and to the children's services professionals. Professionals recognised that parents were being provided with emotional support, a role that they found difficult to fulfil when focusing on the needs of the children. The parents' understanding of the issues was also recognised as supporting their engagement with the child protection process and services provided.

Advocacy for parents with learning disabilities has been reported as cost effective in terms of reduced service use and positive outcomes for parents and children (Bauer et al., 2013).

(See Appendix B Policy and Legal Context for the legal considerations relevant to advocacy support.)

Parenting groups

In Tarleton et al.'s (2006) study, parents were found to benefit greatly from attending parents' groups. The groups provided peer support and friendship as well as information/knowledge regarding parenting issues. Parents and professionals involved with parenting groups stressed that they should:

- be held at a neutral venue not associated with children and families services
- be held on a regular day and at a regular time
- provide transport – one service provided an escorted minibus – to reduce time spent by workers picking up and dropping off parents
- have a structure and ground rules which enable parents to share their experiences with other parents in a safe environment and to learn from and support each other
- provide specific information for parents of school-age children, as many services only support families until children start school.

Other research has confirmed the benefits of parenting groups. Llewellyn (1997) recognises that parents learn from watching each other, while McGaw et al. (2002) and Gustavsson and Starker (2017) stress the activities and conversations that improve the parents' social capital and social networks. Gustavsson and Starker (2017) highlight how the social workers involved in running these groups are trusted and seen as allies whom parents will ask for support, information and contacts.

Parent training

A Canadian learning disability service has been providing a parent education programme since 1981. Self-directed learning was developed to teach basic childcare, health and safety skills to parents with learning disabilities. "Controlled field studies with 33 parents found that 96% of the self-trained skills rapidly reached the same level seen in competent parents and were maintained for as long as 3.5 years".

Most of the parents also received other support services. These were families facing considerable difficulties: child protection services were involved in 79% of families and all were living below the poverty line (Feldman, 2004).

More recent research still indicates that skills can be taught to parents (for systematic reviews of outcome studies see Feldman, 1994; Wade, Llewellyn, and Matthews, 2008). Interventions focusing

on health and safety as well as parent training in the home have shown improvements in parents' skills (Llewellyn, 2003; McGaha, 2002).

Research by Pearson (2019) found that adults with learning disabilities could be taught about attachment using a DVD. The parents were found to have increased knowledge regarding attachment behaviours. This research did not however investigate whether the increased knowledge had any impact on their behaviour with their child. The authors suggest that this type of teaching needs to be combined with 'invivo' feedback on parenting skills, using video techniques (see below).

This conclusion, that parenting skills can be taught, is backed by a review of four international randomised control trials, which indicated that mothers may gain increased parenting skills from parents training programmes. The review points out that the evidence is low grade and that few fathers were included in the trials (Coren, Ramsbotham and Gschwandter, 2018).

Group education combined with home-based intervention

Research shows that a combination is more effective than either home-based intervention or a group education programme on its own.

A review of mainstream parenting programmes to prevent child abuse and neglect found that programmes that included peer support and focused on direct coaching were more effective than parent education alone (Chaffin, Bonner & Hill, 2001).

Similarly, McGaw, Ball and Clark (2002) found that parents with learning disabilities who received a group education programme, together with home-based intervention, experienced a statistically significant improvement in self-concept and awareness, in comparison with a control group of parents with learning disabilities who received home-based intervention only.

A further analysis of the same programmes indicated that group work on its own was less effective than programmes which also included concurrent home-based interventions (McGaw and Newman, 2005).

The charity Mellow Parenting Programme adapted their pre- and post-birth attachment-based programmes for mothers with learning disabilities. The 'Mellow Futures' programme uses both group work and provision of a mentor to support the mothers in transferring their new understandings into their parenting at home.[29]

Tarleton and Turner (2015) found that mothers really enjoyed attending Mellow Futures programmes and reported having learned how to care for their baby while looking into the issues that impact on their parenting, such as difficulties in their own childhood. Parents had also, often for the first time, developed supportive peer relationships with other mothers.

[29] www.mellowparenting.org/.

Professionals involved with the families also reported, for the majority of mothers, improvement in the mother's relationship with and care for her baby and lowering of the level of concerns for the baby's welfare.

Similarly, Glazemaker and Deboutte (2013) have described the successful modification of the group-based Positive Parenting Programme for parents with learning disabilities.[30]

Video interaction guidance

Video interaction guidance is being used to support parents to improve their interactions with their children. Simply put, the parent is videoed interacting with their child. The video is then reviewed with the positive interactions pointed out. There are a few studies, such as Pethica and Bigham's (2018) case study of one mother, showing that the mother's interaction with her child had improved. However, a randomised control trial recently found that VIG did not impact on observed parenting for the 'average' parent with learning disabilities but may benefit parents with lower adaptive functioning (Hodes et al., 2017).

Preventative approaches are key to safeguarding and promoting children's welfare

Best practice survey (Social Care Institute for Excellence, 2006) recognised that there is a continuum of prevention:

- Preventing unnecessary problems from arising by addressing specialist low-level parent support needs for information, equipment and assistance
- Preventing harm to children and family crises, which could lead to children being accommodated
- Supporting parents whose children have been removed from home, with a view to reuniting families where possible
- Post-crisis support aimed at anticipating and preventing future difficulties.

Addressing needs at all stages of this continuum requires:

- changing eligibility criteria to take parenting needs into account so that responses can be put in place at lower levels of need than currently recognised within adult services
- recognition that if parenting needs are responded to within the adult social care framework then children are less likely to be in need
- recognition that needs relating to impairment/illness and disabling barriers must be addressed before making judgements about parenting capacity
- bringing in children's social work expertise at points where – working in partnership with adult social care – it is possible to prevent further problems arising

[30] This is often known as 'Triple P', www.triplep.net/glo-en/home/.

- having clear policies and procedures for joint involvement in critical situations with the aim of building resilience and ability to cope in the future
- joint commissioning and joint working in order to provide flexible, ongoing support where required and anticipation of changes in needs in relation to both impairment/illness and family circumstances.

Conclusion

There has been much research about parents with learning disabilities in recent years. It is clear that most parents with learning disabilities are not receiving the type of support that is known to bring about improved outcomes for children.

The potentially poorer outcomes for the children, if their parents are not provided with support, has been highlighted alongside the barriers their parents face to being able to parent well, as their learning disability is often only one element of complex circumstances.

The research has highlighted the need for early, consistent, and appropriately tailored support for parents and their children, based on positive relationship-based partnerships between professionals and families. The Six 'T's practice framework provides one framework for establishing that mutually respectful partnership.

Appendix B Policy and legal context

The original *Good practice guidance* in working with parents with a learning disability was published by the Department of Health and Department for Education and Skills in 2007 and updated by the Working Together with Parents Network[31] in 2016.

It is beyond the remit of this basic, interim update to provide full details of current government policy that support the features of good practice identified in this *Good practice guidance*; only a broad outline is therefore provided, leaving the detail for a future, full refresh of the *Guidance* by the Department of Health and Social Care, Disability Unit or other relevant government department, following publication of the government's national Disability Strategy in 2021/2022.

The policy context for supporting parents with learning disabilities and their children

Two key aspects of government policy are that:

- Disabled people and their families should experience equality of opportunity
- Adult and children's services, across health, education and social care, should work together to provide early help and improve outcomes for children and their families.

The White Paper **Improving Life Chances of Disabled People** set out the general policy aim that all disabled people (including people with learning disabilities) "should have full opportunities and choices to improve their quality of life and…. be respected and included as equal members of society" (Prime Minister's Strategy Unit, 2005, p.7).

The earlier White Paper **Valuing People** included within its strategy for people with learning disabilities a specific policy aim of: "Supporting parents with learning disabilities in order to help them, wherever possible, ensure their children gain maximum life chance benefits" (Department of Health, 2001, Sub-objective 7.4).

The subsequent White Paper **Valuing People Now** confirmed that the starting point for the new strategy was the re-affirmation of the four guiding principles set out in Valuing People:

- Rights: People with learning disabilities and their families have the same human rights as everyone else.
- Independent living: All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

[31] www.wtpn.co.uk.

- Control: Having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.
- Inclusion: Being able to participate in all aspects of the community and to have the support to do so.[32]

Valuing People Now also stated:

> we need to do more to make sure that adults' and children's services work more effectively together to improve identification of families that need extra support and carry out more effective assessments of their needs to ensure that families with complex needs, including parents with learning disabilities, receive the right level of support at an earlier stage.[33]

Fulfilling Potential – Making it happen reiterated government commitment to supporting disabled people to realise their aspirations.

> … all disabled people, whatever their age or background, to have the opportunity to fulfil their potential – to lead full and active lives that are valued by society. We cannot achieve this unless we have modern and responsive public services to support all disabled people, their carers and families.[34]

For children and parents generally, the policy aim, originally set out in **Every Child Matters**: **Change for Children**, and reflected in the **Children Act 2004**, is that every child, whatever their background or their circumstances, should have the support they need to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic wellbeing.

Local authorities are required to take the lead in drawing up strategic Children and Young People's Plans to identify where these outcomes need to be improved and how to bring about these improvements. **The Childcare Act 2006** places a duty on local authorities to reduce inequalities in wellbeing between young children in their area.

---

[32] Department of Health (2009), p.30.

[33] Department of Health (2009), para 3.56 at p.94, http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf.

[34] Office for Disability Issues, Department for Work and Pensions (2013), https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320745/making-it-happen.pdf.

A key aim of current policy is to shift the focus from dealing with the consequences of difficulties in children's lives, to preventing things from going wrong in the first place. Initiatives intended to help achieve this include:

Early intervention – a public policy approach which encourages preventative intervention in the lives of children or their parents, to prevent later detrimental life outcomes such as poor educational attainment or poor health. Programmes can be universal or targeted. **Professor Munro's review** of the child protection system also emphasised the importance of early help, which was accepted by the government.[35]

Life Chances Strategy: improving the life chances of disadvantaged children and families – the Government first outlined its strategy in the 2016 Queen's Speech. Early intervention plays a central role in the strategy.

Healthy Child Programme – a universal NHS programme for the health and wellbeing of children led by health visitor teams; **Family Nurse Partnership** – an evidence-based preventative programme for vulnerable first-time young mothers; **Healthy Start** – vouchers for milk, fruit, vegetables and vitamins, where parents are in receipt of certain benefits; **peri-natal mental health** – focusing on the prevention, detection and management of mental health problems that occur during the peri-natal period.

Sure Start children's centres – ensuring early childhood services in the local area are integrated and providing services tailored to the needs of the young children and their parents; **Parenting classes** – to be considered a normal part of parenting, similar to attending ante-natal classes.

The Common Assessment Framework (CAF) or Early Help Assessment (EHA) helps to identify needs of children and families and make a plan to meet those needs. It is a shared tool for use by all local agencies delivering early help. Its purpose is to provide a co-ordinated response and make decisions at the earliest opportunity to improve the situation for the child and their family.

The Lead Professional is the person responsible for co-ordinating actions identified in the assessment and will be a single point of contact for children with additional needs who are being supported by more than one service or practitioner.

The National Service Framework for Children, Young People and Maternity Services recognised that some parents, including those with learning disabilities, require:

- an early identification of their support needs
- specialised forms of support
- collaborative arrangements between adult and children's social care.[36]

[35] The Munro Review of Child Protection (2011).

[36] Department of Health and Department for Education and Skills (2004a), pp.44, 69.

National Service Framework for Children, Young People and Maternity Services: Core Standards

Markers of good practice:

1. Multi-agency working to support parenting is outlined in any local strategic and service plans.
2. Information and services to support parenting (by both mothers and fathers and carers) are available and coordinated through local multi-agency partnerships.
3. Support for all parents with pre-school children is available from early years settings including nurseries, Sure Start local programmes and Children's Centres.
4. Parents whose children are experiencing difficulties (for example, because of learning disabilities and/or difficulties or challenging behaviour) receive early support and evidence-based interventions; requirements for local provision are identified in strategic planning.
5. Collaborative arrangements are in place between services for adults and those for children and families to ensure effective joint assessment and support/treatment to enhance parent's parenting capacity and protect and promote the wellbeing and welfare of children.
6. Adults caring for looked after children have early, accessible, multidisciplinary support.
7. Primary Care Trusts and Local Authorities ensure that local parents are involved in the planning and delivery of services, with representation from all local communities and groups.

Supporting People continues to be an important part of the policy framework for services to people with learning disabilities as many (including those who are parents) are either living in, or require, supported housing in order to live independently in the community. Supporting People provides housing-related support services. Local authorities are required to analyse the need for such services in their area and develop (with relevant partners) commissioning strategies to meet these needs. The policy is also intended to encourage the development of packages of care and support jointly between housing, health and social care (Department of the Environment, Transport and the Regions, 2001, p.13).

In addition, the **Homelessness Reduction Act 2017** makes homelessness prevention a statutory duty, requiring earlier intervention and an enhanced advice duty. Prevention services must be offered to anyone eligible and threatened with homelessness. Where support needs are highlighted, good referral processes/protocols should be in place for early intervention. This can involve assisting the person to stay in their current accommodation or helping them to find a new place to live.

A personalised housing plan will be drawn up which sets out the 'reasonable steps' the authority and the applicant will take (and other agencies/people as appropriate). 'Reasonable steps' are required to be tailored to the individual, and the plan to be realistic.

Direct payments are monetary payments made to individuals who request them to meet some or all of their eligible care and support needs. The legislative context for direct payments is set out in the Care Act 2014, the Care and Support (Direct Payments) Regulations 2014 and section 117(2C) of the Mental Health Act 1983. The policy behind them is that they provide independence, choice and control by enabling people to commission their own care and support in order to meet their eligible needs.

The local authority has a key role in ensuring that people are given relevant and timely information about direct payments, so that they can make a decision whether to request a payment, and, if doing so, are supported to use and manage the payment appropriately.

The local authority will need to be satisfied that the person has capacity to make a request for direct payments. "Assumptions should not be made due to the existence of a particular condition, nor on whole groups of people." (Chapter 12.12 Care and Support Statutory Guidance.)

The availability of direct payments should be included in the universal information service that all local authorities are required to provide.

For full details, see chapter 12 Care and Support Statutory Guidance issued under the Care Act 2014.

Wellbeing, prevention, information and advice, and shaping the market of care and support services are the key principles underlying the **Care Act 2014**. Assessments are to be carried out based on the appearance of need, rather than any formal diagnosis. Local authorities and their partners have a statutory duty to co-operate in the exercise of their functions relevant to care and support, including those to protect adults.

The legal context for supporting parents with learning disabilities and their children

Legislation and guidance set out the responsibilities of organisations and the rights of individuals. For example:

- The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- The United Nations Convention on the Rights of the Child (UNCRC)
- The Equality Act 2010
- The Human Rights Act 1998
- The Care Act 2014
- Care and Support (statutory guidance)
- Working Together to Safeguard Children 2018 (statutory guidance)
- Court Orders and Pre-proceedings – for local authorities (2014) (statutory guidance)

- The Children Act 1989 guidance and regulations Volume 2: care planning, placement and case review (2015) (statutory guidance)

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

UNCRPD includes provision for the right to accessibility of information and services (art 9), access to justice (art 13) and respect for home and the family (art 23). In particular, art 23(2) provides "States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities."

The United Nations Convention on the Rights of the Child (UNCRC)

UNCRC includes provision for the child's best interests to be a primary consideration (art 3), the right to know and be cared for by his/her parents, as far as possible (art 7), the right to express views (art 12) and parental primary responsibility for the child (art 18). In particular, art 18(2) provides "States Parties shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities."

The Equality Act 2010 and the Human Rights Act 1998

Application of the *Good practice guidance* principles is an essential step towards ensuring that the rights of parents with learning disabilities, and those of their children, are respected in accordance with the Equality Act 2010 sections 20 (reasonable adjustments) and 149 (duty to eliminate discrimination and to advance equality of opportunity); and articles 6 (fair trial), 8 (private life) and 14 (prohibition of discrimination) of the European Convention on Human Rights, incorporated into UK law by the Human Rights Act 1998.

It is important to recognise that services such as the provision of information, assessment, the putting in place of services to meet assessed need, and action taken to protect a child from significant harm – are all covered by the Equality Act 2010, requiring service providers to make 'reasonable adjustments' to ensure that a disabled person receives the same level of service as a non-disabled person, and by the Human Rights Act 1998 to ensure fair processes and full participation.

In addition, both adult services and children's services authorities have a duty under the Equality Act to advance equality of opportunity for disabled people (including parents) in their local population. This applies to all their functions and means that they should take pro-active steps to ensure equal access and equal treatment.

The Care Act 2014

The Act deals with the reform of adult social care and support legislation, setting out the (then) new statutory principle of promoting adults' wellbeing and preventing, delaying or reducing the development of care and support needs.

Wellbeing principle – section 1: this statutory principle applies to all the functions under Part One of the Care Act (including care and support and safeguarding). Local authority decisions must promote the adult's wellbeing.

Prevention – section 2: local authorities must provide preventative services i.e. services that help prevent, delay or reduce the development of care and support needs.

Integration – section 3: places a duty on local authorities to carry out their care and support functions with the aim of integrating services with those provided by the NHS or other health-related services.

Information and advice – section 4: requires local authorities to make available information about the services they provide for disabled people; and to ensure that disabled people know about both local authority services and any other relevant services provided by other organisations. Whether or not someone is eligible for help from adult social care, local authorities must provide information about other sources of support and advice.

The local authority must ensure that there is an accessible information and advice service that meets the needs of its population. Information and advice must be open to everyone who would benefit from it. People access information and advice from a wide variety of sources. The authority should take account of information standards[37] published by the Information Standards Board for Health and Social Care under the provisions of the Health and Social Care Act 2012 (Chapter 3.18, Care and Support).

Local authorities should ensure that information supplied is clear. Information and advice should only be judged as clear if it is understood and able to be acted upon by the individual receiving it. Local authorities will need to take steps to evaluate and ensure that information and advice is understood and able to be acted upon (Chapter 3.19, Care and Support).

The Equality Act 2010 gives disabled individuals the right to 'reasonable adjustments' to be made in the way information is provided, so that it is accessible to them. The Act places a responsibility on public bodies to ensure that disabled people generally have equal access to their services (including the provision of information).

Co-operation – sections 6-7: create a general duty to co-operate between the local authority and other organisations which have functions relevant to support and care. This includes a duty on the local authority itself to ensure co-operation between its adult care and support, housing, public health and children's services.

How to meet needs – section 8: examples are given of the ways in which the local authority may meet a person's needs under the Act.

Assessments – sections 9, 10, 11 and 12: address when an assessment of need must be carried out, what the assessment should cover, that regulations may specify further details about the assessment process, including requiring that the assessment be appropriate and proportionate.

[37] http://www.hscic.gov.uk/isce/publication/isn.

Eligibility – section 13: requires local authorities to determine whether a person has eligible needs after they have carried out a needs assessment. Regulations set out eligibility criteria, including the national minimum level of eligibility at which local authorities must meet a person's care and support needs.

Independent advocacy support – sections 67 and 68: place a duty on local authorities in certain specified circumstances to arrange for an independent advocate to be available to facilitate the involvement of an adult who is the subject of an assessment, care or support planning or review.

When considering the provision of an independent advocate, whether in the context of the Care Act or otherwise, the requirements of the Equality Act 2010 and the Human Rights Act 1998 should also be taken into account to ensure that a parent is able to fully participate in the process.

Care and Support (statutory guidance)

This guidance provides the full detail and examples of how the Care Act is to be implemented in practice. For example, at para 6.104 the guidance states that a formal diagnosis of a learning disability (and other disabilities) is not required for the local authority to be satisfied that the adult's needs for care and support is due to a physical or mental impairment or illness.[38]

Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children (2018) (statutory guidance)

This guidance sets out in detail local authority statutory functions under the 1989 and 2004 Children Acts. This includes specific duties in relation to children in need and children suffering, or likely to suffer, significant harm under section 17 and section 47 Children Act 1989. Procedures to assess need and provide help and organisational responsibilities are set out in chapters 1 and 2.

Reference is made to the 2016 *Good practice guidance* at Appendix B Further Sources of Information, where there is a hyperlink to the document.[39]

An earlier version of Working Together (2010) provided six pages of information about parents with a learning disability at part 2 chapter 9 pp.278–283 – Lessons from Research. (It can still be accessed from the archived document.[40]) Reference was also made to the 2007 *Good practice guidance* both in footnotes and hyperlinked in the references section.

Court Orders and Pre-proceedings – for local authorities. Department for Education (2014) (statutory guidance)

This guidance provides a high-level guide to the law, setting out the different private and public law orders, including placement and adoption orders and processes relating to care and court proceedings (including pre-proceedings and post-proceedings).

---

[38] https://www.gov.uk/guidance/care-and-support-statutory-guidance.
[39] Working Together to Safeguard Children 2018 (publishing.service.gov.uk).
[40] 00305-2010DOM-EN.pdf (nationalarchives.gov.uk).

The guidance mentions the need for early identification and support for parents with a learning disability. Several references are made to the need to consider capacity issues at the earliest opportunity.[41]

The Children Act 1989 guidance and regulations Volume 2: care planning, placement and case review (June 2015) (statutory guidance)

This guidance sets out the functions and responsibilities of local authorities and partner agencies under Part 3 of the Children Act 1989, which concerns the provision of local authority support for children and families. In particular it describes how local authorities should carry out their responsibilities in relation to care planning, placement and case review for looked after children to safeguard and promote the welfare of the looked after child and to act as good corporate parents to enable each looked after child to achieve his/her full potential in life.

At para 3.79, in the context of assessing parental capacity for change, the guidance states it is particularly important to assess issues (such as severe learning disability) and to explore whether, if they formed part of the grounds for a care order, the parent has had sufficient support in addressing them before a child returns home.[42]

Public Law Working Group Report (PLWG)– Recommendations to achieve best practice in the child protection and family justice systems (March 2021)

The working group, which was led by Mr Justice Keehan, identified issues and challenges and made 47 core recommendations. The child's voice and their wellbeing are key themes throughout as is partnership working and achieving cultural change.

The recommendations cover: Support for and work with families prior to court proceedings; The application; Case management; Supervision orders; S20/76 accommodation.

Best practice guidances were attached as appendices to the Report: Best practice guidance for support for and work with families prior to court proceedings; Best practice guidance for the case management and the application; Best practice guidance for S20/76 accommodation.

A standalone report on special guardianship orders, with accompanying best practice guidance, was published in June 2020.

Appendix E of the Report (Best Practice Guidance: Support for and work with families prior to court proceedings) states that:

> Care proceedings are the option of last resort. The purpose of the PLO pre-proceedings process is not purely one of assessment where the local authority is thinking about making an application to the court. It represents a genuine opportunity to work closely with families by offering help and support to address their recognised needs in a bid to negate the need

[41] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306282/Statutory_guidance_on_court_orders_and_pre-proceedings.pdf.
[42] Stat guidance template (publishing.service.gov.uk).

> to issue care proceedings. This BPG aims to achieve the best outcomes for children, young people and their families. It is supported and endorsed by the ADCS, ADSS Cymru, and the wider membership of this working group. This guidance is intended to provide a practical step-by-step guide to practitioners and relevant stakeholders in order to achieve a degree of consistency, but not the standardisation, of approaches across the jurisdiction.

The PLWG recommended that the Social Work Evidence Template (SWET) should bring greater focus to work carried out during pre-proceedings as well as clarity around the legal test for removal, i.e. why now? The SWET was originally designed to support a consistent, analytical approach to presenting social work evidence to the family courts while complementing other standardised forms required by the Public Law Outline. It has been updated accordingly.[43]

Vulnerable witnesses family court rules

Part 3A of the Family Procedure Rules 2010 came into force November 2017 supplemented by a new Practice Direction 3AA.

Part 3A sets out the court's duties and powers in relation to helping parties whose ability to participate or to give evidence in family proceedings may be diminished by reason of their vulnerability, to ensure a fair hearing.

The Practice Direction states that it is the duty of the court and all parties to the proceedings to identify any party or witness who is a vulnerable person, at the earliest possible stage of any family proceedings. (The SWET provides an opportunity to do so in the Case Management Issues and the Statement of Procedural Fairness sections.)

Participation directions can be made – for example that an intermediary should be appointed. Rule 3A.7 sets out the relevant factors, which include, in particular, whether the party or witness suffers from a mental disorder or has a significant impairment of intelligence or social functioning, has a physical disability or physical disorder or is undergoing medical treatment.

The court should also consider the ability of the party or witness to: (a) understand the proceedings and their role in them, (b) put their views to the court, (c) instruct their representative before, during and after the hearing, and (d) attend the hearing without significant distress.

If the court decides that a vulnerable party, vulnerable witness or protected party (represented by the Official Solicitor) should give evidence, there must be a 'ground rules hearing' first to agree how the witness can be helped to give their best evidence, e.g. breaks, the way questions are phrased etc.[44]

---

[43] Recommendations to achieve best practice in the child protection and family justice systems FINAL REPORT (MARCH 2021) Microsoft Word - March 2021, report (final).docx (judiciary.uk).

[44] PRACTICE DIRECTION 3AA - VULNERABLE PERSONS: PARTICIPATION IN PROCEEDINGS AND GIVING EVIDENCE (justice.gov.uk); PART 3A - VULNERABLE PERSONS: PARTICIPATION IN PROCEEDINGS AND GIVING EVIDENCE (justice.gov.uk).

Guidance from the (former) President of the Family Division – Family Proceedings: Parents with a learning disability

In April 2018, the then President of the Family Division, Sir James Munby, issued guidance relating to family proceedings involving parents with a learning disability. He referred to relevant cases, research, intermediaries, new Family Proceedings Rules and the *Good practice guidance*. He said

> My primary purpose in issuing this Guidance is to bring to the attention of practitioners and judges, and to commend for careful consideration and application by everyone, the very important *Good practice guidance on working with parents with a learning disability* issued by the Working Together with Parents Network and the Norah Fry Centre in September 2016[45]

Case law examples

Parenting with support

Re D (A Child) (No 3) Tarleton, Ward and Howarth (2006) *Finding the Right Support?*[46] provided many of the good practice examples included in the 2007 *Good practice guidance*. This research was referred to by the President of the Family Division in **Re D (A Child) (No 3) [2016] EWFC 1** at paras 27–29 and again at para 164 et seq. when referring to the 2006 Northern Ireland case **Re G and A**.

> 164(7) Children of parents with learning difficulties often do not enter the child protection system as the result of abuse by their parents. More regularly the prevailing concerns centre on a perceived risk of neglect, both as the result of the parents' intellectual impairments, and the impact of the social and economic deprivation commonly faced by adults with learning difficulties. It is in this context that a shift must be made from the old assumption that adults with learning difficulties could not parent to a process of questioning why appropriate levels of support are not provided to them so that they can parent successfully and why their children should often be taken into care. At its simplest, this means a court carefully inquiring as to what support is needed to enable parents to show whether or not they can become good enough parents rather than automatically assuming that they are destined to fail. The concept of "parenting with support" must move from the margins to the mainstream in court determinations.[47]

Re G and A:

> The concept of "parenting with support" must underpin the way in which courts and professionals approach wherever possible parents with learning difficulties. Courts must be aware of the distinction between direct and indirect discrimination. Careful consideration must be given to the assessment phase and i the application of the threshold test. Too narrow a focus must not be placed exclusively on the child's welfare with an accompanying failure to

[45] Family Proceedings: Parents with a Learning Disability | Courts and Tribunals Judiciary.
[46] http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/rightsupport.pdf.
[47] http://www.bailii.org/ew/cases/EWFC/HCJ/2016/1.html.

address parents' needs arising from their disability which might impact adversely on their parenting capacity. Joint training needed for adult and children's services.[48]

Failure to apply the *Good practice guidance*

Some of the cases in English courts referring to the importance of complying with the *Guidance*:

Medway v A & Others (Learning Disability: Foster Placement) [2015] EWFC B66 (2 June 2015). References to the *Guidance* at para 103 et seq.

> 106. It is clear that the purpose of the 2007 DoH Good Practice Guidance, namely to ensure that appropriate steps are taken to ensure services and training are in place to meet the needs of parents with disabilities, has yet to be met in Medway; and there appears to have been little if any awareness of the DoH Good Practice Guidance's recommendations shown by Medway's practice in this case.
>
> 112 … but I do find that … her practice betrayed a significant unawareness of the issues set out in the DoH Good Practice Guidance.[49]

Kent CC v A Mother [2011] EWHC 402 (Fam). References to the *Guidance* at para 132 et seq.

> 134. The Guidance contains much more important advice, but I have selected the passages cited above because it is manifestly clear that, in this case, Kent County Council failed to comply with those passages of the Guidance on many occasions. That is hardly surprising, because the clear impression I formed from the evidence of the social workers called to give evidence in the hearing is that they were completely unfamiliar with the Guidance.
>
> 135. All social workers, and family support workers, working with children and families need to be trained to recognise and deal with parents with learning disabilities. The Guidance issued by central government needs to be followed.[50]

A Local Authority v G (Parent with Learning Disability) (Rev 1) [2017] EWFC B94 (18 December 2017). The availability or lack of resources could not justify the local authority pressing for more drastic orders; the lack of a protocol for dealing with parents with a learning disability reflected in the approach taken within the case; those working with the mother should have been trained to work with parents with a learning disability, not just working with people with a learning disability; work should have continued with the parents after the children had been removed, not least to assess whether necessary changes were being made; training was not adapted to the mother's needs, nor were the trainers trained in learning disability.

---

[48] Re G and A (Care Order: Freeing Order: Parents with a Learning Disability) [2006] NIFam 8.

[49] http://www.bailii.org/ew/cases/EWFC/OJ/2015/B66.html.

[50] http://www.bailii.org/ew/cases/EWHC/Fam/2011/402.html.

> To describe the Guidance as a 'counsel of perfection' is to give a charter to ignore it which should be robustly challenged (para 215) HHJ Dancey.[51]

PQR (Supported Parenting For Learning Disabled Parents) (Rev 1) [2018] EWFC B72 (30 October 2018).

> The local authority should, in my view, reflect on how different these boys' early years would have been, if the mother's disability had been recognised earlier and the recommendations contained in the guidelines had been followed. (Para 28) HHJ Greensmith.[52]

S (Recognising the Role of the Independent Reviewing Officer (IRO) [2018] EWFC B71. The court requested additional evidence from the local authority including evidence of how the guidance in respect of parents with a learning disability had been followed. As a result, the new plan included ongoing support from a family mentor who was a trained foster carer with experience of working with parents with learning disabilities, an advocate for school and health meetings and a referral to adult social care for a Care Act assessment.

> The court is confident that this package of support … meets the obligations of the local authority to follow the Guidelines. (Para 11) HHJ Greensmith.[53]

C (A Child: Care Proceedings) [2020] EWFC B46 (06 January 2020).

> On the other hand, LA's evidence and conduct in these proceedings have demonstrated that, in a number of respects, they have not understood the recommendations in re D and the updated WTPN Guidance referred to above and integrated them into their practice when dealing with learning disabled parents …. TM'S evidence also demonstrated that she did not adequately understand the concept of parenting with support or that the fact that learning disabled parents may need support, of varying kinds, throughout a child's minority does not in itself mean that they cannot bring up their children. [para 96]
>
> I am concerned that the criticisms I have made within this judgment might be indicative of a systemic failure to implement the guidance I have referred to. I invite the LA to consider whether that is the case and, if so, what steps need to be taken to address it. I hope they will do so. [para 97] DJ Duddridge.[54]

Assessments

Re C [2014] EWCA Civ 128.

> Targeted and suitable expert assessments are required.

---

[51] A Local Authority v G (Parent with Learning Disability) (Rev 1) [2017] EWFC B94 (18 December 2017) (bailii.org).

[52] https://www.bailii.org/ew/cases/EWFC/OJ/2018/B72.html.

[53] S (Recognising The Role of the Independent Reviewing Officer (IRO)) [2018] EWFC B71 (08 November 2018) (bailii.org).

[54] C (a Child : Care Proceedings) [2020] EWFC B46 (06 January 2020) (bailii.org).

A Local Authority v G (Parent with Learning Disability) (Rev 1) [2017] EWFC B94 (18 December 2017). Delays in assessment created conflict with the children's timescales; if support is provided in a timely and efficient manner, focusing on a solution for the children within their timescales is not inconsistent with a focus on supporting the parents.[55]

Communication

Derbyshire County Council and SH [2015] EWFC B102.

> I have to question whether [the social worker] was able to communicate orally with SH. Did SH fully understand what was being asked of her or said to her? Did SH feel able to express herself appropriately? Did [the social worker] discuss issues with SH in a language which she would understand? I conclude that there is at least a possibility here that the negative assessment of SH stemmed in part from the fact that [the social worker] and SH were simply not on the same wave-length when discussing matters.

Re G and A [2006] (Care Order: Freeing Order: Parents with a Learning Disability) [2006] NIFam 8.

> The courts must be careful to ensure that the supposed inability of parents to change might itself be an artefact of professionals' ineffectiveness in engaging with parents in appropriate terms.

Re G (Care: Challenge to Local Authority's Decision) [2003] 2 FLR 42.

> Where for whatever reason – whether physical or mental disability, illiteracy or the fact that English is not their mother-tongue – parents cannot readily understand the written word, the local authority must take whatever ameliorative steps are necessary to ensure parents are not for that reason prevented from playing a full and informed part in the decision-making process.

Independent advocates

Re C (Lay Advocates) [2019] EWHC 3738 (Fam). Two psychologists recommended advocates be appointed for the parents. Both the Legal Aid Agency and HM's Courts & Tribunals Service (HMCTS) refused to fund them. The High Court ordered HMCTS to fund them.

> I take the view that if provision is not made for a lay advocate for each of these parents there would be a grave risk of a potential breach of their article 6 rights. Absent the appointment of a lay advocate, there would be a real likelihood that they would not be able to engage with the proceedings to such a degree that neither of them had a fair hearing. [para 20] Mr Justice Keehan.[56]

Fair processes

A Father v SBC & Others [2014] EWFC 6.

---

[55] A Local Authority v G (Parent with Learning Disability) (Rev 1) [2017] EWFC B94 (18 December 2017) (bailii.org).

[56] https://www.bailii.org/ew/cases/EWHC/Fam/2019/3738.html.

> The local authority's duties under Article 8 include the duty to ensure that the processes by which decisions about children are made are fair and that the parents are sufficiently involved in that process.

Re G (Care: Challenge to Local Authority's Decision) [2003] 2 FLR 42.

> Article 8 guarantees substantive and procedural rights i.e. fairness at all stages of child protection before, during and after proceedings. Parents must be involved in the decision-making process. Even if circumstances justify intervention, LA is not absolved of its duty to act fairly.

A&B (Children) (deaf parent – assessment and practice) [2021] EWFC 10. This case raises many issues of equal relevance and importance to parents with learning disabilities.

Para 86 – The duty for social workers and local authorities to consider and implement procedural fairness is not just a box to be ticked at the end of the SWET. The SWET represents sworn evidence of how the local authority has fulfilled its duty to guarantee a parent's Article 6 rights to a fair trial throughout its involvement; see Munby J (as he then was) in **Re L (Children) (Care: Assessment: Fair Trial) [2002] 2 FLR 730**:

> 151. The state, in the form of the local authority, assumes a heavy burden when it seeks to take a child into care. Part of that burden is the need, in the interests not merely of the parent but also of the child, for a transparent and transparently fair procedure at all stages of the process – by which I mean the process both in and out of court …[57]

Re C (Lay Advocates)(No.2) [2020] EWHC 1762 (Fam). The court ruled that HMCTS should pay for an advocate while supporting parents in court and the Legal Aid Agency should pay for an advocate supporting parents in communicating with their solicitor/barrister out of court.

> I remain of the view, as set out in my previous judgment, that the appointment of a lay advocate for this mother and for this father was and is essential to ensure their Article 6 rights are not infringed and to ensure that they are enabled to participate fully and effectively in these public law proceedings. [Para 18] Mr Justice Keehan.[58]

Joint working

Re S [2013] EWCA Civ 1073.

> At the heart of the problems in this case has been the division of the LA's work between adult social services and children's services … they did not work together or form a consistent view of the case.

---

[57] A & B (Children) (deaf parent - assessment and practice) [2021] EWFC 10 (09 February 2021) (bailii.org).

[58] https://www.bailii.org/ew/cases/EWHC/Fam/2020/1762.html.

Conducting proceedings where there is a learning disability

Re A (A Child) [2013] EWHC 3502 (Fam). How to conduct proceedings where a party is vulnerable due to a learning disability.

Timeliness

PQR (Supported Parenting For Learning Disabled Parents) (Rev 1) [2018] EWFC B72 (30 October 2018)

> A review of the chronology of the local authority's involvement reveals that the local authority was able to identify key aspects of the mother's personality which should have put it on notice that the mother potentially had a learning disability. [Para 26] HHJ Greensmith.[59]

Parental responsibility

Re G (Care: Challenge to Local Authority's Decision) [2003] 2 FLR 42.

> Article 8 guarantees substantive and procedural rights i.e. fairness at all stages of child protection before, during and after proceedings. Parents must be involved in the decision-making process. Even if circumstances justify intervention, LA is not absolved of its duty to act fairly. The fact that a LA has parental responsibility for children does not entitle it to take decisions about those children without reference to, or over the heads of, the children's parents. The fact that the LA also has parental responsibility does not deprive the parents of their parental responsibility.

The responsibilities of adult social care

Adult social care have responsibilities laid down by both care legislation and children's legislation.

The Children Act 1989 places a general duty on local authorities to safeguard and promote the welfare of children.

When responding to a referral for care services, adult social care have a statutory responsibility to check whether the person has parenting responsibilities for a child under 18 and if so to explore any parenting and child-related issues.

Adult social care services should liaise with children's social care services to ensure that there is a joined-up approach when carrying out assessments.[60]

The responsibilities of children's services

Information

The Children Act 1989, Schedule 2, Paragraph 1 (2) requires local authorities to publish information about services available to children in need and their families and take steps to ensure that such families know about services (including those provided by the voluntary sector). The

[59] https://www.bailii.org/ew/cases/EWFC/OJ/2018/B72.html.

[60] Working Together 2018, chapter 1.

Equality Act 2010 gives disabled individuals the right to 'reasonable adjustments' to be made in the way information is provided, so that it is accessible to them and places a responsibility on public bodies to take action to ensure that disabled people have equal access to their services (including the provision of information).

Services to children in need and their families

The Children Act 1989 places a general duty on local authorities:

> to safeguard and promote the welfare of children within their area who are in need; and so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs.[61]

A child is 'in need' if they are unlikely to experience a reasonable standard of health or development without assistance, or if their health or development is likely to be significantly impaired without assistance, or if they are disabled.

When a child is, or may be, 'in need' an assessment should be carried out using the approach set out in the statutory guidance Working Together 2018.

Assessments should cover the following three domains:

- The child's developmental needs
- The capacities of parents/carers to respond to these needs
- The impact of wider family and environmental factors on parenting capacity and on children.[62]

Policy guidance recognises that there are some families where children do not meet the 'children in need' criteria, and parents do not reach adult social care eligibility criteria, and yet support is necessary in order to prevent problems arising:

> For example, a mother with a mild learning disability may not reach the criteria for help from an adult services team and her child's standard of care may not be sufficiently poor to meet the criteria for children's services intervention. However, the failure to recognise the need for early intervention to provide support to the child and family on a planned basis from both children's and adult services may result in the child's current and future development being impaired.[63]

The provision of early help services should form part of a continuum of help and support to respond to the different levels of need of individual children and families. Where need is relatively low level, individual services and universal services may be able to take swift action. For other emerging needs a range of early help services may be required, coordinated through an early help assessment.

---

[61] Children Act 1989, section 17.

[62] Working Together to Safeguard Children 2018 (publishing.service.gov.uk).

[63] Department of Health et al, 2000, Paragraph 3.58.

Where there are more complex needs, help may be provided under section 17 of the Children Act 1989 (children in need) or through action taken under section 47 of the Children Act 1989. It is important that there are clear criteria for taking action and providing help across this full continuum. Having clear thresholds for action which are understood by all professionals, and applied consistently, including for children returning home from care, should ensure that services are commissioned effectively and that the right help is given to the child at the right time.

Some of these services may be delivered to parents e.g. help with cleaning, budgeting, food shopping, cooking etc. but should always be evaluated to demonstrate the impact they are having on the outcomes for the child.[64]

If a local authority considers that a young carer may have support needs, they must carry out an assessment under section 17ZA of the Children Act 1989. The local authority must also carry out such an assessment if a young carer, or the parent of a young carer, requests one. Such an assessment must consider whether it is appropriate or excessive for the young carer to provide care for the person in question, in light of the young carer's needs and wishes. The Young Carers' (Needs Assessment) Regulations 2015 require local authorities to look at the needs of the whole family when carrying out a young carers' needs assessment. Young carer's assessments can be combined with assessments of adults in the household, with the agreement of the young carer and adults concerned.

Section 96(12) of the Children and Families Act 2014 requires local authorities to take reasonable steps to identify the extent to which there are young carers within their area who have needs for support. These changes align with changes in the Care Act requiring local authorities to offer assessments of need to adult carers and to identify adult carers with unmet needs within their local population.

The specific needs of young carers should be given sufficient recognition and priority in the assessment process. Further guidance can be accessed at Recognised, valued and supported: Next steps for the Carers Strategy (2010).[65]

Where the local authority children's social care decides to provide services, a multi-agency child in need plan should be developed with the agreement of the child and key family members, which sets out which agencies will provide which services to the child and family. The plan should set clear measurable outcomes for the child and expectations for the parents. The plan should reflect the positive aspects of the family situation as well as the weaknesses.

Direct payments can be made to parents in lieu of services provided under section 17 of the Children Act 1989.

---

[64] Working Together 2018, page 16.
[65] Working Together 2018.

Protection of children from significant harm

Where a local authority has cause to suspect that a child in their area is suffering, or is at risk of suffering significant harm, they have a duty to make enquiries to establish whether action is required to safeguard or promote the child's welfare and a right to compulsorily intervene if such concerns are substantiated.[66]

Detailed statutory guidance about managing individual cases is set out in chapter 1, Working Together (2018) and in Court Orders and Pre-proceedings for local authorities (2014).

Children may be provided with alternative accommodation, with their parents' consent, in order to safeguard their welfare; or where considered necessary, the local authority may apply to the court for an Emergency Protection Order so that a child can be removed to a place of safety. Where parents/caregivers are unwilling to co-operate with an assessment, the court can be asked to grant a Child Assessment Order[67].

Where it is decided that the child is not at risk, or is not at continuing risk, of significant harm, children's social care should discuss the case with the child, parents and other professionals; determine whether support from any services may be helpful and help secure it; and consider whether the child's health and development should be re-assessed regularly against specific objectives and decide who has responsibility for doing this.[68]

Where enquiries confirm that a child is suffering, or at risk of significant harm, an initial child protection conference should be convened, involving the child, parents and all relevant agencies. The initial child protection conference should take place within 15 working days of a strategy discussion, or the strategy discussion at which section 47 enquiries were initiated if more than one has been held; consider whether any professionals with specialist knowledge should be invited to participate; ensure that the child and their parents understand the purpose of the conference and who will attend; and help prepare the child if he or she is attending or making representations through a third party to the conference.

Information should be given about advocacy agencies and the family told that they may bring an advocate, friend or supporter.

If the conference decides that the child is at continuing risk of significant harm, an outline child protection plan should be drawn up. A key worker, who is a qualified experienced social worker, should be designated to co-ordinate inter-agency responses. S/he also has responsibility for ascertaining the child's wishes and feelings. A core group of professionals should be identified who will develop the detailed child protection plan and ensure that it is implemented.[69]
The overall aim of a child protection plan is to:

---

[66] Children Act 1989, section 47.
[67] Children Act 1989, section 43.
[68] Working Together 2018, page 47.
[69] Working Together 2018, page 47.

- ensure the child is safe from harm and prevent him or her from suffering further harm;
- promote the child's health and development; and
- support the family and wider family members to safeguard and promote the welfare of their child, provided it is in the best interests of the child.[70]

The Working Together statutory guidance sets out the procedures and responsibilities for reviewing the impact of service interventions. Where it is considered necessary, a local authority may apply to the court for a care order (committing the child to the care of the local authority) or supervision order (putting the child under the supervision of a social worker, or a probation officer).

See also statutory guidance Court Orders and Pre-proceedings for local authorities. Department for Education (2014) and The Children Act 1989 guidance and regulations Volume 2: care planning, placement and case review (June 2015) (statutory guidance).[71]

[70] Working Together 2018, page 51.

[71] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306282/Statutory_guidance_on_court_orders_and_pre-proceedings.pdf; https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/441643/Children_Act_Guidance_2015.pdf.

Appendix C Resources

1. Making information accessible

Accessible Information Standard (DCB1605 Accessible Information)
From 1st August 2016 onwards, all organisations that provide NHS care and/or publicly-funded adult social care are legally required to follow the Accessible Information Standard. The Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

The Standard is made up of a Specification and Implementation Guidance, both of which were revised in August 2017.[72]

CHANGE
The Words to Pictures Team: a team of people with learning disabilities who work with an illustrator to produce information in an easy read format using easy words and pictures. The Team produces CD Roms (picture banks) of hundreds of pictures for organisations working with people with learning disabilities. Illustrators in CHANGE can also draw additional pictures as and when necessary.

CHANGE turns other organisations' documents, posters, flyers, leaflets and annual reports into an accessible format, and people with learning disabilities provide training around how to make information accessible and how to use the Picture Bank CD Roms.

For more information contact: CHANGE, Unity Business Centre, 26 Roundhay Road, Leeds LS7 1AB. Email info@changepeople.org; tel. 0113 242 6619; https://www.changepeople.org/

Mencap
The charity provides accessible communication and easy read services, including training. For information and advice about these services, contact Mencap https://www.mencap.org.uk/contact-us-mencap

Making websites accessible
Website owners have a legal duty under the Equality Act 2010 to ensure that services provided via the web are accessible to disabled people.

Building on this, accessibility regulations came into force for public sector bodies on 23 September 2018 – Public Sector Bodies (Websites and Mobile Applications) (No. 2) Accessibility Regulations 2018.[73]

[72] https://www.england.nhs.uk/ourwork/accessibleinfo/.
[73] https://www.gov.uk/guidance/accessibility-requirements-for-public-sector-websites-and-apps#history.

Photosymbols
Photosymbols are a popular set of pictures for making easy read information for people with a learning disability. Subscription needed.[74]

Communication Card
CHANGE has produced a communication card that can be used to show how a person likes to communicate and receive information.[75]

Books - Beyond Words
Beyond Words is a charity that provides books and training to support people who find pictures easier to understand than words.[76]

2. Joint protocols and care pathways: good practice examples

In 2007 the Social Care Institute for Excellence published a resource for developing protocols for joint working across adult and children's health and social care to support disabled parents and their children. This includes a protocol template.[77]

An increasing number of agencies are developing joint protocols. Some are referred to in the *Guidance*. Contact details to find out more are as follows:

Bath and North East Somerset Council: Protocol for Supporting Disabled Adults in their Parenting Capacity

Cornwall: Working Together to support parents with a learning disability

Dorset County Council: A Multi-agency Protocol for Working with Parents with Learning Disabilities living in Dorset

Leeds Integrated Maternity Care Pathway for women with LD:
https://www.leeds.gov.uk/docs/168%20-%20Leeds%20Maternity%20Care%20Pathway%20for%20women%20with%20LD.pdf

Norfolk County Council: Protocol for joined-up services

[74] https://www.photosymbols.com/.
[75] https://www.changepeople.org/getmedia/4ad774ac-23ec-4609-b1a1-13280b07a483/CHANGE-Communication-Card-v2.
[76] https://booksbeyondwords.co.uk/.
[77] https://www.scie.org.uk/publications/guides/guide19/.

3. Resources for working with parents with learning disabilities

The Working Together with Parents Network supports professionals who work with parents who have learning disabilities/difficulties. Members include parents and carers with learning disabilities/difficulties and professionals from the social care, health, independent advocacy and legal sectors. 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 their legal rights are respected so that they get better support.[78]

WTPN Regional Directory of Services: a signpost to services that support parents with learning difficulties/disabilities and uphold the general principles of the *Good practice guidance on working with parents with a learning disability*.[79]

The British Institute of Learning Disabilities aims to ensure people with learning disabilities are valued equally, participate fully in their communities and are treated with dignity and respect. A full range of resources is available online.[80]

Enabling Parenting with Support: Effective working with parents with learning disabilities, by Deborah Chinn (2012), is a training pack available from Pavilion Publishing and Media Ltd.[81]

Camden Society – How Do I? is an app for mobile devices which links video content to objects in homes and workplaces, helping people to complete tasks without needing supervision.[82]

PARENTS Need ... A service for families with learning disabled parents and for the schools, colleges, local authorities, advocates and charities that work with them.[83]

Healthy Start (Australia) – Helping professionals support parents with learning difficulties is an initiative that supports professionals working with parents who have learning difficulties. It provides information and resources for practitioners, managers, researchers and policy makers and aims to improve outcomes for both parents and children.[84]

---

[78] www.wtpn.co.uk.
[79] http://www.bristol.ac.uk/media-library/sites/sps/documents/wtpn/PDF%20WTPN%20REGIONAL%20DIRECTORY%20JUNE%202021.pdf.
[80] https://www.bild.org.uk/resources/.
[81] https://www.pavpub.com/learning-disability/ld-children/enabling-parenting-with-support.
[82] https://wearehowdoi.com/lifeskills.
[83] https://www.parentsneed.co.uk/.
[84] https://www.parentingrc.org.au/programs/healthy-start/.

4. Assessment tools

ParentAssess: A comprehensive assessment framework for parents who have learning disabilities or additional needs.[85]

Parent Assessment Manual by Sue McGaw, Kerry Keckley, Nicola Connolly and Katherine Ball.[86]

Learning Curves: The assessment of parents with a learning disability – A Manual for practitioners, by Penny Morgan and Andy Goff, Norfolk Area Child Protection Committee.[87]

Parenting Assessments for parents with learning difficulties – guidance from the Working Together with Parents Network[88]

British Psychological Society Good Practice Guidance for Clinical Psychologists when assessing parents with learning disabilities.[89]

5. Person-centred planning

The Foundation for People with Learning Disabilities provides a number of resources relating to person-centred planning.[90]

See also **Circles Network**[91]

6. Parenting skills programmes and resources

Mellow Futures: Adapted Mellow Parenting programme for parents with learning disabilities.[92]

---

[85] https://www.parentassess.com/.
[86] http://www.pillcreekpublishing.com/sue_mcgaw.html.
[87] http://www.norfolklscb.org/wp-content/uploads/2015/09/Corrected-Learning-Curves.pdf.
[88] http://www.bristol.ac.uk/sps/wtpn/resources/.
[89] https://shop.bps.org.uk/good-practice-guidance-for-clinical-psychologists-when-assessing-parents-with-learning-disabilities#:~:text=This%20long%20overdue%20and%20much%20needed%20Good%20Practice,psychologists%20working%20in%20the%20public%20and%20private%20sectors.
[90] http://www.learningdisabilities.org.uk/?view=Search+results&search=person+centred+planning.
[91] https://circlesnetwork.org.uk/who-we-are/.
[92] https://www.mellowparenting.org/our-programmes/mellow-futures/.

Triple P - Positive Parenting Program.[93]

The London Network for Parents with Learning Disabilities: Information and advice for parents with learning disabilities in London.[94]

CHANGE publications: practical handbooks for parents with learning disabilities to have at home for them to read.

- Planning a Baby booklet
- My Pregnancy, My Choice
- You and Your Baby 0-1
- You and Your Baby 1-5

For more information: CHANGE, Unity Business Centre, 26 Roundhay Road, Leeds LS7 1AB; email info@changepeople.org; tel. 0113 242 6619; fax. 0113 242 6142; website[95]

BILD publications:

I want to be a good parent – Five illustrated cards to help parents carry out a range of essential childcare tasks. For use with support from health or childcare workers.

I want to be a good parent – Five illustrated booklets giving practical advice for parents with learning disabilities:

- What's it like to be a parent?
- Children need healthy food
- Children need to be clean healthy and warm
- Children need to be safe
- Children need love

Available from: BILD Publications, BookSource, 50 Cambuslang Road, Cambuslang, Glasgow G32 8NB; email enquiries@bild.org.uk or BILD website.[96]

[93] https://www.triplep.net/glo-en/home/.
[94] https://healthwatchcamden.co.uk/starthere/guide/london-network-parents-learning-disabilities#:~:text=London%20Network%20Of%20Parents%20With%20Learning%20Disabilities%20Network,with%20learning%20difficulties%20and%20workers%20working%20with%20them.
[95] https://www.changepeople.org/#:~:text=CHANGE%20operates%20on%20a%20co-working%20model%20which%20means,co-run%20projects%2C%20co-deliver%20training%20and%20co-create%20accessible%20information.
[96] https://www.bild.org.uk/shop/.

7. Legal proceedings

The Court and Your Child: when social workers get involved. Free accessible information for parents.[97]

Care Proceedings and Learning Disabled Parents: A Handbook for Family Lawyers, by Abigail Bond, Jordan Publishing Ltd.

Meeting the needs of vulnerable clients: Law Society Practice Note for solicitors.[98]

The Official Solicitor. Accessible information.[99]

[97] https://www.judiciary.uk/wp-content/uploads/JCO/Documents/FJC/Publications/Public_Law_booklet-+English.pdf.
[98] https://www.lawsociety.org.uk/topics/client-care/working-with-vulnerable-clients-case-studies.
[99] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/815728/official-solicitor-easy-read-booklet.pdf.

Appendix D Bibliography

Aunos, M, Goupil, G, and Feldman, M. 2003. Mothers with intellectual disabilities who do or do not have custody of their children. *Journal on Developmental Disabilities*, 10, 2, 65–79.

Aunos, M and Pacheco, L. 2013 Changing perspective: Workers' perceptions of inter-agency collaboration with parents with an intellectual disability. *Journal of Public Child Welfare*, 7, 5, 658-674.

Aunos, M, Proctor, L, & Moxness, K. 2010. Turning fights into realities in Quebec, Canada. In G. Llewellyn, R. Traustadottir, D. McConnell, & H. Sigurjonsdottir, Eds., *Parents with intellectual disabilities, past, present and future*, 189–204. West Sussex: Wiley Blackwell.

Bauer, A. , Wistow, G., Dixon, J. and Knapp, M. 2013*. Investing in advocacy interventions for parents with learning disabilities: what is the economic argument? Discussion paper (2860).* Kent: Personal Social Services Research Unit.

Booth, T. and Booth, W. 1997. *Exceptional childhoods, unexceptional children*. London: Family Policy Studies Centre.

Booth, W. and Booth, T. 1998. *Advocacy for parents with learning difficulties*. Brighton: Pavilion Publishing.

Booth, T. & Booth, W. 2004. *Parents with learning difficulties: child protection and the courts*, a report to the Nuffield Foundation on Grant No. CPF/00151/G. Sheffield University, Department of Sociological Studies, www.supportedparenting.com/projects/NuffieldReport.pdf.

Booth, W. and Booth, T. 2004. A family at risk: multiple perspectives on parenting and child protection. *British Journal of Learning Disabilities* 32, 1, 9-15.

Booth T, and Booth, W. 2005. Parents with learning difficulties in the child protection system: Experiences and perspectives. *Journal of Intellectual DisabilitiesI,* 9, 2, 109-129.

Booth, T and Booth, W. 2007. Parental competence and parents with learning difficulties. *Child & Family Social Work*, 1, 2, 81–86.

Booth, T., McConnell, D. and Booth, W. 2005. Temporal Discrimination and Parents with Learning Difficulties in the Child Protection System. *British Journal of Social Work*, 36, 997–1015.

Booth, T., Booth, W. and McConnell, D. 2005. Care proceedings and parents with learning difficulties: comparative prevalence and outcomes in an English and Australian court sample. *Child and Family Social Work*, 10, 4, 353-360.

British Psychological Society 2011. *Good Practice Guidance for Clinical Psychologists when assessing parents with learning disabilities*. http://www.bps.org.uk/system/files/Public%20files/DCP/cat-690.pdf.

Burch, K., Allen, V., Green C., Taylor, V. and Wise, S. 2019. *Research on the number of children in Wales placed into care from parents with learning disability and the reasons behind their removal*. Welsh Government, GSR report number 56/2019.

Care Services Improvement Partnership 2006. *Who's holding the baby? Integrated health and social care child protection project*. www.bedsandhertswdc.nhs.uk/workforce_development/downloads/whb_final_report.pdf

CHANGE, 2005. *Report of national gathering of parents with learning disabilities*. Leeds: CHANGE.

Cleaver, H., Unell, I. and Aldgate, J. 1999. *Children's Needs – parenting capacity: The impact of parental mental illness, problem alcohol and drug use, and domestic violence on children's development*. London: The Stationery Office.

Chaffin, M., Bonner, B. and Hill, R. 2001. Family preservation and family support programs: Child maltreatment outcomes across client risk levels and program types, *Child Abuse & Neglect*, 25, 10, 1269–1289.

Cleaver, H. and Nicholson, D. 2007. *Children living with learning disabled parents*. London: Department for Education and Skills.

Commission for Social Care Inspection 2006. *Supporting Parents, Safeguarding Children: Meeting the needs of parents with children on the child protection register*. London: Commission for Social Care Inspection.

Collings, S. Grace, R. and Llewellyn G. 2017. The role of formal support in the lives of children of mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 3, 492–500.

Collings, S. and Llewellyn, G. 2012. Children of parents with intellectual disability: Facing poor outcomes or faring okay? *Journal of Intellectual and Developmental Disability*, 37, 1, 65–82.

Collings, S., Llewellyn, G. and Grace R. 2017. Home and the social worlds beyond: exploring influences in the lives of children of mothers with intellectual disability. *Child: care, health and development,* 43, 5, 697–708.

Collings, S., Spencer, M., Dew A. and Dowse, L. 2018. She was there if I needed to talk or to try and get my point across: specialist advocacy for parents with intellectual disability in the Australian child protection system. *Australian Journal of Human Rights*, 24, 2, 162–181.

Cox, R., Stenfert Kroese, B. and Evan R. 2015. Solicitors' experiences of representing parents with intellectual disabilities in care proceedings: attitudes, influence and legal processes. *Disability and Society*, 30, 2, 284–298.

Cooke, P. 2005. *ACTing to support parents with learning disabilities*. Nottingham: Ann Craft Trust.

Commission for Social Care Inspection 2006. *Supporting Parents, Safeguarding Children: Meeting the needs of parents with children on the child protection register*. London: Commission for Social Care Inspection.

Coren, E., Ramsbotham, K. and Gschwandter, M. 2018. *Parent training interventions for parents with intellectual disability*. https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007987.pub3/full

Darbyshire, L., V. and Stenfort Kroese, B. 2012. Psychological well-being and social support for parents with intellectual disabilities: Risk factors and interventions. *Journal of Policy and Practice in Intellectual Disabilities*, 9, 1, 40-52.

Department for Education and Skills 2005. *Everything you wanted to know about pooled budgets but were afraid to ask*. www.everychildmatters.gov.uk/_files/1CB4E7D2B038F853D5523B49DD0E2693.doc.

Department for Education and Skills 2003. *The Children Act Report 2002*. London: Department for Education and Skills.

Department for Education and Skills 2004. *Commissioning Checklist: A step by step guide to better planning and commissioning of placements and services for looked after children and children with special educational needs and disabilities in residential schools*. www.everychildmatters.gov.uk/_files/690C3686F70CD128BE1BBEF340B64CA2.pdf.

Department for Education and Skills and Department of Health 2004a. *National service framework for children, young people and maternity services: Core standards*. London: Department of Health. www.dh.gov.uk/assetRoot/04/09/05/66/04090566.pdf.

Department for Education and Skills and Department of Health 2004b. *The national service framework for children, young people and maternity services: Maternity services*. London: Department of Health. www.dh.gov.uk/assetRoot/04/09/05/23/04090523.pdf.

Department of the Environment, Transport and the Regions 2001. *Supporting people: policy into practice*. London: Department of the Environment, Transport and the Regions. www.supporting-people.org.uk/policyguidance.asp.

Department of Health 1993. Approvals and directions for arrangements from 1 April 1993 made under schedule 8 to the National Health Service Act 1977 and sections 21 and 29 of the National Assistance Act 1948. *LAC* (93) 10. London: Department of Health.

Department of Health 2001. *Valuing People: A national strategy for learning disability in the 21st century.* London: The Stationery Office. www.archive.officialdocuments.co.uk/document/cm50/5086/5086.htm.

Department of Health 2009. *Valuing People Now: a new three- year strategy for people with learning disabilities*. London: https://www.base-uk.org/sites/default/files/%5buser-raw%5d/11-06/valuing_people_now_strategy_.pdf

Department of Health 2002a. *National standards on the provision of children's advocacy services*. www.dh.gov.uk/assetRoot/04/01/88/93/04018893.pdf.

Department of Health 2002b. *Protocol on advice and advocacy for parents (Child protection)*. www.dh.gov.uk/assetRoot/04/01/89/00/04018900.pdf.

Department of Health, Department for Education and Employment and Home Office 2000. *Framework for the assessment of children in need and their families*. London: Department of Health. www.archive.official-documents.co.uk/document/doh/facn/facn.htm.

Department for Work and Pensions 2013. *Fulfilling Potential – making it happen*. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320745/making-it-happen.pdf

Dugdale, D. and Symonds, J. 2016. *Fathers with learning disabilities and their experiences of adult social care services*. London: School for Social Care Research and University of Bristol.

Durling, E., Chinn, D. and Scior, K. 2018. Family and community in the lives of UK Bangladeshi parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 31, 6, 1133–1143.

Emerson, E. and Brigham, P. 2014. The developmental health of children of parents with intellectual disabilities: Cross sectional study. *Research in Developmental Disabilities*, 35, 4, 917–921.

Emerson, E., Malam, S., Davides, I. and Spencer, K. 2005. *Adults with Learning Difficulties in England 2003/4*. www.ic.nhs.uk/pubs/learndiff2004.

Family Rights Group. *The highs and lows of kinship care: analysis of a comprehensive survey of kinship carers 2019*. https://frg.org.uk/product/the-highs-and-lows-of-kinship-care-analysis-of-a-comprehensive-survey-of-kinship-carers-2019/

Faureholm, J. 2010. Children and their life experiences in G. Llewellyn, R. Traustadottir, D. McConnell and H. Sigurjonsdottir, Eds. *Parents with intellectual disabilities, past, present and future*, 63–78. West Sussex: Wiley Blackwell.

Feldman, M.A., Varghese, J., Ramsay, J. and Rajska, D. 2002. Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 314–323.

Feldman, M. A. 2004. Self-directed learning of child-care skills by parents with intellectual disabilities. *Infants & Young Children*, 17,1, 17–31.

Glazemaker, I., and Deboutte, D. 2013. Modifying the 'Positive Parenting Program' for parents with intellectual disabilities. *Journal of Intellectual Disability Research*, 57, 616–626.

Goldacre, A. D., Gray, R. and Goldacre, M. J. 2015. Childbirth in women with intellectual disability: characteristics of their pregnancies and outcomes in an archived epidemiological dataset. *Journal of Intellectual Disability Research*, 59, 7, 653–63.

Gudkova T., Hedlund M. and Midjo T. 2019. Supporting children of parents with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disability*, 32, 737–749.

Gur A., Stein M. A. 2019. Social worker perception of grandparent involvement where a parent has an intellectual disability. *Res Dev Disabil*, 92:103427.

Gustavsson, M. and Starke, M. 2017. Groups for parents with intellectual disabilities: A qualitative analysis of experiences. *Journal of Applied Research in Intellectual Disabilities*. 30, 4, 638–647.

Hatton, C., Glover, G., Emerson, E. and Brown, I. 2016. *People with learning disabilities in England 2015: Main report*. London: Public Health England.

Hewitt, O. 2007. What is the effect on a child of having a parent with learning disability? *Tizard Learning Disability Review*, 12, 2, 33–44.

Hindmarsh, G., Llewellyn, G. and Emerson, E. 2017. The social-emotional well-being of children of mothers with intellectual impairment: A population-based analysis. *Journal of Applied Research in Intellectual Disabilities*, 30, 3, 469–81.

Hodges, H. and Bristow, D. 2019. *Analysis of the factors contributing to the high rates of care in Wales*. The Wales Centre for Public Policy. 190715-Analysis-of-Factors-Contributing-to-High-Rates-of-Care-REVISED.pdf (wcpp.org.uk).

Hodes, M., Meppelder, M., de Moor, M., Kef, S. and Schuengel, C. 2017. Alleviating parenting stress in parents with intellectual disabilities: A randomized controlled trial of a video-feedback intervention to promote positive parenting. *Journal of Applied Research in Intellectual Disabilities*, 30, 3, 423–432.

Höglund, B., Lindgren, P., and Larsson, M. 2012. Pregnancy and birth outcomes of women with intellectual disability in Sweden: A national register study. *Acta Obstetricia et Gynecologica Scandinavica*, 91,12, 1381–1387.

Höglund B., Lindgren P., Larsson M. 2012. Newborns of mothers with intellectual disability have a higher risk of perinatal death and being small for gestational age. *Acta Obstet Gynecol Scand*, 91,1409–14.

H M Government 2018. *Working together to safeguard children: A guide to inter-agency working to safeguard the welfare of children*. Working Together to Safeguard Children 2018 (publishing.service.gov.uk)

H M Government 2006. *Common assessment framework for children and young people: Practitioners' guide*. www.ecm.gov.uk/caf.

H M Government 2018. *Information Sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers (July 2018).* Information sharing: advice for practitioners (publishing.service.gov.uk)

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities 2008. Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 21, 4, 296–307.

Kroese, B. S., Hussein, H., Clifford, C. and Ahmed, N. 2002. Social support networks and psychological wellbeing of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15 (4), 324–340.

LaLiberte, T., Piescher, K., Mickelson, N., and Lee, M. H. 2017. Child protection services and parents with intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, Vol 30, Issue 3, 521–532.

Lindblad, I., Billstedt, E., Gillberg, C., and Fernell, E. 2013. An interview study of young adults born to mothers with mild intellectual disability. *Journal of Intellectual Disabilities*, 17, 329–338.

Lindley, B. and Richards, M. 2002. *Protocol on advice and advocacy for parents (Child Protection).* Cambridge: Centre for Family Research.

Lightfoot, E., and LaLiberte, T. 2011. Parental supports for parents with intellectual and developmental disabilities. *Journal of Intellectual and Developmental Disabilities*, 49, 5, 1–7.

Llewellyn, G. 1997. Parents with intellectual disability learning to parent: the role of experience and informal learning. *International Journal of Disability, Development and Education*. 44, 3, 243–261.

Llewellyn, G. 2013. Parents with intellectual disability and their children: Advances in policy and practice. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 2, 82–85. https://doi.org/10.1111/jppi.12033.

Llewellyn, G., Hindmarsh, G. 2015. Parents with intellectual disability in a population context. *Current developmental disorders reports*, 2, 119–126.

Llewellyn, G., McConnell, D., Ferronato, L. 2003. Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, 27, 3, 235–251.

Lloyd, E., ed. 1999. *What works in parenting education?* Ilford: Barnardo's.

Masson, J. M., Pearce, J. F., and Bader, K. F. 2008. Care Profiling Study. *Ministry of Justice Research Report,* Vol. 08, No. 4. London: Ministry of Justice and Department of Children, Schools and Families. http://www.rip.org.uk/files/prompts/p6/care_profiling_study.pdf.

Mayes, R., Llewellyn, G., and McConnell, D. 2008. Active Negotiation: Mothers with Intellectual Disabilities Creating Their Social Support Networks. *Journal of Applied Research in Intellectual Disabilities*, 21, 4, 341–350.

Mayes, R., Llewellyn, G., and McConnell, D. 2006. Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research*, 8, 120–131.

McConnell, D., Feldman, M., Aunos, M., and Prasad, N. 2011a. Parental cognitive impairment and child maltreatment in Canada. *Child Abuse & Neglect*, 35, 8, 621–632.

McConnell, D., Feldman, M., Aunos, M., and Prasad, N. 2011b. Child maltreatment investigations involving parents with cognitive impairments in Canada. *Child Maltreatment*, 16, 1, 21–32.

McConnell, D., ane Llewellyn, G. 2002. Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law*, 24, 3, 297–317.

McGaw, S., Ball, K. and Clark, A. 2002. The effect of group intervention on the relationships of parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 4, 354–366.

McGaw, S. and Newman, T. 2005. *What works for parents with learning disabilities?* Barnardo's.

McGaw, S. Shaw, T., Scully, T. and Pritchard, C. 2010. Predicting the unpredictable? Identifying high risk versus low risk parents with intellectual disabilities. *Child Abuse & Neglect* 34, 9, 699–710.

McGaw, S., Shaw, T., and Beckley, K. 2007. Prevalence of psychopathology across a service population of parents with intellectual learning disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 1, 11–22.

McGaha, D. 2002. Development of parenting skills in individuals with an intellectual impairment: An epigenetic explanation. *Disability & Society*, 17, 1, 81–91.

McGhee, J. and Hunter, S. 2011. The Scottish children's hearings tribunals system: a better forum for parents with learning disabilities? *Journal of Social Welfare and Family Law*, 33, 3, 255–266.

Morgan, P. and Goff, A. 2004. *Learning Curves: The assessment of parents with a learning disability*. Norfolk Area Child Protection Committee.

Munro, E. 2011. *The Munro Review of Child Protection. Final Report: a child-centred system*. London: Department for Education. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/175391/MunroReview.pdf.

Office for Disability Issues, Office of the Deputy Prime Minister 2004. *Delivering housing adaptations for disabled people: A good practice guide*. ODPM. http://www.odpm.gov.uk/index.asp?id=1152861.

O'Hara, J. and Martin, H. 2003. Parents with learning disabilities: a study of gender and cultural perspectives in East London. *British Journal of Learning Disabilities*, 31, 18-24.

O'Neill, A. 2011. Average and bright adults with parents with mild cognitive difficulties: The Huck Finn syndrome 20 years later. *Journal of Applied Research in Intellectual Disabilities*, 24, 6, 566–572.

Prime Minister's Strategy Unit 2005. *Improving the life chances of disabled people*. London: Cabinet Office. www.strategy.gov.uk/work_areas/disability/

Social Care Institute for Excellence 2005. *Helping parents with learning disabilities in their role as parents*. www.scie.org.uk

Pearson, T., Chaisty, F., and Stenfert Kroese, B. 2019. Teaching young adults with intellectual disabilities about early parent-child attachment behaviours using an educational DVD. *International Journal of Developmental Disabilities*, 65, 3, 143–151.

Pethica, S. and Bigham, K. 2018. Stop talking about my disability, I am a mother: Adapting video interaction guidance to increase sensitive parenting in a young mother with intellectual disability. *British Journal of Learning Disabilities*, 46, 2, 136–142.

Redley, M. 2009. Understanding the social exclusion and stalled welfare of citizens with learning disabilities. *Disability and Society*, 24, 4, 489–501.

Ronai, C. R. 1997. On loving and hating my mentally retarded mother. *Mental Retardation*, 35, 417–432.

SCIE 2005. *Helping parents with learning disabilities in their role as parents*. http://www.scie.org.uk/publications/briefings/briefing14/index.asp.

SCIE 2006. *Supporting disabled parents and parents with additional support needs*. https://www.scie.org.uk/publications/knowledgereviews/kr11.pdf.

Sigurjónsdóttir, H., and Rice, J. 2018. 'Evidence' of neglect as a form of structural violence: Parents with intellectual disabilities and custody deprivation. *Social Inclusion*, 6, 2, 66–73.

Slayter, E. and Jensen, J. 2019. Parents with intellectual disabilities in the child protection system. *Children and Youth Services Review*, 98, 297–304.

Stewart, A., MacIntyre, G. and McGregor, S. 2016. *Supporting parents with learning disabilities in Scotland: Challenges and opportunities*. Glasgow: Scottish Commission for Learning Disability.

Strnadová, I., Collings, S., Loblinzk, J. and Danker, J. 2019. Parents with intellectual disabilities and their perspective of peer support: "It depends on how they give it". *Journal Applied Research in Intellectual Disability*, 32, 879–889.

Swain, P. and Cameron, N. 2003. 'Good Enough Parenting': Parental disability and child protection. *Disability & Society*, 18, 2, 165–177.

Tarleton, B. 2013. Expanding the Engagement Model: The Role of the Specialist Advocate in Supporting Parents With Learning Disabilities in Child Protection Proceedings: *Journal of public child welfare*, 5, 5, 675–690.

Tarleton, B. and Porter, S. 2012. Crossing no man's land: a specialist support service for parents with learning disabilities. *Child and Family Social Work*, 17, 2, 233–43.

Tarleton, B. and Turner, W. 2015. *Mellow Futures: Parent Pioneers project evaluation*. Bristol: School for Policy Studies, University of Bristol.

Tarleton, B., Turney, D., Merchant, W. and Tilbury, N. 2018. *Successful professional practice when working with parents with learning difficulties*. Bristol: University of Bristol.

Tarleton, B., Ward, L. and Howard, J. 2006. *Finding the Right Support: A review of issues and positive practice in supporting parents with learning difficulties and their children*. Bristol: University of Bristol. www.baringfoundation.org.uk/FRSupportSummary.pdf.

Tymchuck, A. 1992. Predicting adequacy of parenting by people with mental retardation. *Child Abuse and Neglect*, 16, 165–178.

Wade, C., Llewellyn, G. and Matthews, J. 2008. Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21, 4, 351–366.

Weiber, I., Tengland, P. A., Berglund, J., and Eklund, M. 2014. Social and healthcare professionals' experiences of giving support to families where the mother has an intellectual disability: Focus on children. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 293–301.

Wickström, M., Hoglund, M., and Larsson, M. 2017. Increased risk for mental illness, injuries, and violence in children born to mothers with intellectual disability: A register study in Sweden during 1999–2012. *Child Abuse and Neglect*, 65, 124–131.

Wołowicz-Ruszkowska, A. and McConnell, D. 2017. The experience of adult children of mothers with intellectual disability: A qualitative retrospective study from Poland. *Journal of Applied Research in Intellectual Disability*, 30, 482–491.

Working Together with Parents Network (WTPN), 2009. *Supporting parents with learning disabilities and difficulties – Stories of positive practice*. Bristol: Norah Fry Research Centre, University of Bristol.

Working Together with Parents Network (WTPN)
wtw-pn@bristol.ac.uk
www.wtpn.co.uk

This publication has been produced by the Working Together with Parents Network,
Norah Fry Centre for Disability Studies, School for Policy Studies, University of Bristol.

It contains public sector information licensed under the Open Government Licence v3.0.
www.nationalarchives.gov.uk/doc/open-government-licence/version/3/