University of BRISTOL

Esmée Fairbairn FOUNDATION

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

Good practice guidance on working with parents with a learning disability (2007)

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

SEPTEMBER 2016

The Working Together with Parents Network update of the DoH/DfES Good Practice Guidance on working with parents with a learning disability (2007)

For some time now, there has been an urgent need to issue an updated version of the Good Practice Guidance and to press for compliance with its basic principles in order to respect the human rights of parents with learning disabilities and those of their children. It had been hoped that the Department of Health would take forward this work and those discussions continue. In the meantime, the Working Together with Parents Network (WTPN) has produced this basic, interim update.

The original DH/DfES Good Practice Guidance on working with parents with a learning disability (2007) can be found here

http://webarchive.nationalarchives.gov.uk/20080910224541/dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119

The 2007 Good Practice Guidance

The '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
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

Five key features of good practice

The Guidance sets 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

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."
http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/4009.htm

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?

Over the past few years, the 2007 Good Practice Guidance appears to have fallen into disuse; professionals working with parents with learning disabilities either have not heard of the Guidance, or they fail to apply it.

One reason for this may be that some elements of the Guidance are clearly out of date (references to the Disability Discrimination Act 1995, but not the Equality Act 2010; to Working Together 2006, rather than 2015; Primary Care Trusts rather than Clinical Commissioning Groups etc.) although the essential principles contained in the Guidance remain as valid today as they were in 2007.

Another reason may be that the Guidance is not prominently referred to in other relevant guidance e.g. Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children (2015).

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 2015 (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.

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 in child protection proceedings, 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.

"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.*
http://www.bailii.org/ew/cases/EWHC/Fam/2011/402.html

What changes have been made?

- Contact details have been updated in the good practice examples and in Appendix C Resources. Obsolete references have been removed.
- Where research was referred to as "forthcoming", the publication dates have been inserted.
- Although para 1.2.4 was shown twice in the original version, this has not been changed in the update so as to keep the existing numbering for ease of reference/comparison.
- References to the Care Act 2014 and Care and Support Statutory Guidance added.
- Appendix B – substantial update.
- Appendix C – new resources added.
- Appendix D – new references added and others updated.

Removed references to:	**Replaced by references to:**
Working Together 2006	Working Together 2015
Disability Discrimination Act 2005	Equality Act 2010
Primary Care Trusts	Clinical Commissioning Groups
Fair Access to Care Services Guidance on eligibility criteria for adult social care. Department of Health, 2002	The Care Act 2014, the Care and Support (Eligibility Criteria) Regulations (2015), and the Care Act Statutory Guidance Care and Support
The Common Assessment Framework for Children and Young People: Practitioners' Guide, HM Government, 2006	Early identification, assessment of needs and intervention – The Common Assessment Framework (CAF) for children and young people: A guide for practitioners, HM Government, 2009 And references to Early Help Assessments, Working Together 2015, Care and Support Statutory Guidance
What To Do If You're Worried A Child Is Being Abused. HM Government, 2006	What To Do If You're Worried A Child Is Being Abused – advice for practitioners. HM Government, 2015
Statutory guidance on making arrangements to safeguard and promote the welfare of children under section 11 of the Children Act 2004, HM Government 2007	Working Together to Safeguard Children 2015
Information sharing: Practitioners' Guide	Information Sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers. (March 2015)
Protocol on Advice and Advocacy for Parents (Child Protection)	The Protocol of Advice and Advocacy for Parents in Child Protection Cases and the Code of Practice for Professional Advocacy

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
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 resources

Appendix D Bibliography

Introduction and Executive Summary

What is the purpose of this good practice guidance?

The purpose of this practice 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.

The guidance should be read in conjunction with the legislation and guidance referred to in Appendix B, in particular:

- The Care Act 2014, and 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, 2015.

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 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 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 effectively support parents with learning disabilities.

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 disability discrimination 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 and bring up their children, and that parents with learning disabilities have equal access to family support services.

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, 2015.

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 sets 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; 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.

1.1 Accessible information and communication

Accessible information and communication is crucial to enabling parents with learning disabilities to engage with services and to therefore 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:

- Easy Read versions of leaflets
- Audio and/or visual information on CD/DVD/MP3
- 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 Connexions 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 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."*[1]

[1] Quotations given are from parents with learning disabilities consulted during the course of writing this good practice guidance.

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 be, 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, and about 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.

"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 should happen in ways which are accessible to individuals with learning disabilities.

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 don't 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.

Sometimes information is given and communication happens in meetings involving a number of professionals (such as child protection conferences: see also Section 2). It is important to make information and communication accessible in this context as well. 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 early 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 (2015) (see charts on pages 30-51). 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 (www.scie.org.uk).

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 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
- 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.

From 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:

- Pregnant women 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 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

One local Practice Guidance document includes the following agreed referral procedures between adult and children's services:

"Where there are no concerns for the child's welfare, but the parent is unable to provide the appropriate level of care due to disability, parenting support will be offered from the Adult Social Care Team, through a Community Care Plan.

Where Adult Social Care teams are aware of concerns for a child's welfare, a referral should be made to the Children and Young People service for an assessment.

Where children's teams become aware that a parent may have a learning disability, a referral to the Learning Disability Team should be made".

Essex County Council, 2006. Practice Guidance: Referral and Joint Working Arrangements for working with parents and carers who have a learning disability, p.3. Further details from: Kate Evans, Service Manager, Family Centre and Family Group Conferences,

kate.evans@essexcc.gov.uk or kate.evans@raineronline.org.uk

1.2.4 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 at an early stage, to prevent avoidable difficulties arising.

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

One joint protocol agreed between children's and adult services recognises:

"Services should be targeted at families who have additional need which means a different interpretation of the criteria relating to the threshold for service provision than that currently operated by specialist teams.

The combination of impairment and parenting responsibilities within the overall context of the individual family's circumstances may generate a higher degree of need for support than a personal assessment of the disabled/ill adult alone.

Disabled parents or children of disabled parents should automatically be entitled to an assessment".

Norfolk County Council, 2006. Enabling parents with a disability or long-term illness: Joint Policy and Protocol, p.7.

1.2.5 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.

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 they are entitled to.

1.2.6 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 2015, or a section 47 enquiry to establish whether a child may be suffering harm.

This means that a range of professionals who are in contact with children may need to consider, using the Common Assessment Framework/Early Help Assessment, the possibility of parental learning disability and its impact on children. Children's social care will also need to consider the impact and needs associated with learning disability when assessing children in need, and in safeguarding children.

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 2015 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 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.

Good practice in assessment of parents with learning disabilities

Working Together 2015, 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.

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).

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".

(Tarleton et al, 2006)

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.

(Tarleton et al, p.54)

1.3.2 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.

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

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
- 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.

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"

(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".

1.3.4 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."

1.3.5 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 and places them at an unnecessary disadvantage.

1.3.6 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[2]

Jake is 13 and lives with his mother and 2 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.

1.3.7 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 by independent sector services and advocates.

[2] Good Practice examples concerning individual families are anonymised descriptions of cases provided by some of the services consulted for this good practice guidance.

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.

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 different points of their family's life cycle for two main reasons.

Firstly, 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. Secondly, 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

The Family Support Unit at the Home Office funded Home-Start and the Ann Craft Trust to run a three year project, providing volunteer supporters to parents with learning disabilities.

Volunteers received specialist training. A total of 18 families were provided with the service, some over the three year period. Referring professionals were positive about the project, as were most of the parents. A number of large families were referred to the project, whereas it had initially been expected that most referrals would concern prospective parents and parents with babies and young children. These families would have benefited from support at an earlier stage. A common problem experienced by families was harassment and violence from neighbours, and a number of them had to move house because of this.

(Cooke, 2005)

1.4.2 Where a need for long-term support with parenting tasks is identified, it should form part of the community care 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 has a learning disability. She had three children taken into care and didn't know how to ask for help from people or services. Then she met Dean, and 18 months ago they had a baby. Connecting Parents successfully advocated for them to keep their child and things are going well. Della and Dean have been connected to another couple who have really good values and want to support the family as a whole. Dean had said that he wanted more input into the parenting and has been supported to attend a group for Dads. He has 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)

For more information please contact Rebecca Taylor http://www.grapevinecovandwarks.org/ rtaylor@grapevinecovandwarks.org or call 024 7663 1040

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.

1.5 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 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 Advocacy and self-advocacy should be made available to help parents access and engage with services.

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. 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 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 Independent advocacy should always be provided where children are the subject of a child protection plan and/or care proceedings are instituted so that the parents can participate fully and effectively in the proceedings, as is their legal right.

Any parent involved in a child protection conference and/or care proceedings should be informed about local and national sources of independent advocacy. It is particularly important that parents with learning disabilities have access to independent advocacy in these situations. 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 very important that parents have access to independent advocacy at an early stage and also that advocates have appropriate skills and knowledge of both learning disability and child protection issues.

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 (2015) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/419595/Working_Together_to_Safeguard_Children.pdf
- Information Sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers (2015) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/419628/Information_sharing_advice_safeguarding_practitioners.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) http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4018893.pdf
- Independent Advocacy in Child Protection – Guidance for Policy Makers, NCB (2013) https://secure.toolkitfiles.co.uk/clients/22965/sitedata/files/Advocacy_in_CP_-_Policy_Ma.pdf

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
- Information sharing between relevant agencies and professionals
- 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 interests to be paramount. 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.

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 in order 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.

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 guidance sets out the standards for children's advocacy services (Department of Health 2002c). It is important (and required under the Equality Act 2010) 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 the majority of 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 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 – as much as possible – involved 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.

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 be learning disabled 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 with learning disabilities 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 through to the conduct 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"

(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."

Taken from the Circles Network Website 2016
http://www.circlesnetwork.org.uk/lifestory.asp?slevel=0z128z146&parent_id=146&renleewtsapf=172

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 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 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".

A Child's Journey through Placement, Vera Fahlberg, 1994

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 which 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.

One key issue for parents with learning disabilities involved in court proceedings is their need for 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.

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.

"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

Good practice in supporting parents with learning disabilities depends on a commissioning strategy jointly developed and agreed between 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 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.

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 schools 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 sometimes 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 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

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.

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 of the Children Act 2004.

"The key advantage of pooled funding is that it opens up the prospect of original thinking about how better outcomes might be achieved. It permits thinking that is independent of any unhelpful traditions, vested interests, ways of working and constraints on the spending of funds that have hitherto existed."

Everything you wanted to know about pooled budgets but were afraid to ask, www.everychildmatters.gov.uk/_files/1CB4E7D2B038F853D5523B49DD0E2693.doc p.6.

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"

(Department of Health, 2001, p.23)

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, adult learning disability services and children's social care pooled resources to develop a 'shared care' service for families affected by parental learning disability.

This matches families with experienced foster carers who share the care of children and make a long-term commitment to supporting the family.

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). It is therefore important 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. (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

A Local Safeguarding Children Board identified that resources were required to make child protection conferences and related documentation accessible to parents with learning disabilities, and to provide advocacy support. The Assistant Director for Social Services (Learning Disability) and the Director of Children's Services agreed to jointly fund such resources.

3.3.3 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 time-frame for drawing up the strategy should take account of what is required to consult effectively.

"Children on the child protection register said their parents needed:

- *Practical help*
- *Therapeutic help*
- *Clear communication [about what needed to change]; and*
- *Time to get 'back on track'."*

(Commission for Social Care Inspection, 2006, p.19)

3.3.4 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. It is helpful if this includes mainstream services such as midwifery and health visiting.

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 workers 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.

There is, however, an increasing body of evidence 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.

What do we mean by "learning disability"?

The White Paper, Valuing People, states that learning disability 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); which started before adulthood, with a lasting effect on development".
>
> (Department of Health, 2001, p.14)

It is important to recognise that:

- 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)
- It can therefore be difficult to clearly demarcate those parents who have learning disabilities and those who do not

(This is a summary of the useful discussion in McGaw and Newman, 2005, pp. 8-14.)

In the context of parenting, it is more helpful to identify support needs associated with learning disability than to take a rigid approach to the definition of learning disability. Parents with learning disabilities may have support needs associated with impairment, but they may also have support needs associated with other factors such as poor health or inadequate housing.

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'.

This practice guidance is about helping practitioners to promote good practice in fulfilling their statutory responsibilities in terms of both supporting parents and safeguarding and promoting children's welfare. Therefore it is more appropriate to use the term 'parents with learning disabilities' because this is the term that is used within the legislation and statutory guidance. However, 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.

What do we know about the needs and experiences of families, in contact with social care, where at least one parent has learning disabilities?

Almost all the information we have about parents with learning disabilities concerns those who are in contact with social care, and it mostly concerns 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; and we currently know very little about the experiences of fathers with learning disabilities, although research is now being undertaken in this area.

Estimates of the total number of parents with learning disabilities in the United Kingdom vary widely, from 23,000 to 250,000. What is clear, however, is that there are increasing numbers of

parents with learning disabilities in contact with services. Over the last decade or so, clinical psychologists have reported an increase in requests for assessments, and community learning disability teams have seen an increase in the number of parents with learning disabilities on their caseloads. Most children and family teams have at least one family affected by parental learning disability on their caseloads (see Booth and Booth, 2005).

There are also varying estimates of the proportion of parents whose children are removed from their care. It would appear, from a national survey of people with learning disabilities[3], that about 40% of parents are not living with their children. They are more likely to be living with their children if they are living with other relatives (particularly in the case of mothers), and fathers are more likely to be living with their children than mothers. Six out of ten mothers, who live either on their own or with a partner, are not living with their children aged under 18[4].

In one local authority area, about a sixth of family court care proceedings concerned children with at least one parent who has learning disabilities and in about 75% of cases children were permanently removed from their family (Booth et al, 2005). However, analysis of case files across 10 local authority areas found that in less than a fifth of cases involving parents with learning disabilities were their children removed, 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, 2007).

There is anecdotal evidence of local variations in social care practice and court decisions.

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

Parents with learning disabilities, who are in contact with social care, often experience poverty and unemployment; poor housing and difficult neighbourhoods; and lack of information (Social Care Institute for Excellence, 2005). While these are factors experienced by most families in contact with children's social care, parents with learning disabilities have particularly high levels of need, often experiencing severe poverty and inadequate housing (Cleaver and Nicholson, 2007).

Moreover, the lack of information experienced by poor families generally is compounded for parents with learning disabilities by the inaccessibility of most forms of information.

Research on parenting support generally, finds that it is very difficult for stressed families to benefit from such support when they face disadvantages such as poverty, poor health and difficult housing situations (Moran et al, 2004). Social care services, therefore, often need to work with other agencies to attempt to, for example, improve a family's housing situation.

---

[3] Secondary analysis of data from Emerson et al. 2005

[4] These figures were provided by Eric Emerson in a secondary analysis of data from Emerson et al. 2005

"I want my children to have a nice house and a garden to play in, and a good education. I want the support to get these things."[5]

Families affected by parental learning disability are also particularly likely to experience negative attitudes, and worse, from those with whom they come into contact. For example, small scale studies (e.g. Cooke 2005) and messages from parents with learning disabilities themselves (e.g. CHANGE 2005) indicate that harassment and bullying, and sometimes violence and financial or sexual exploitation, can be a major problem for parents with learning disabilities and their children.

Most parents with learning disabilities who receive core assessments from children's social care also experience other difficulties such as "poor mental and physical health, domestic violence, growing up in care, or substance misuse" (Cleaver and Nicholson, 2007).

Parents with learning disabilities may also have low self-esteem and lack confidence, primarily because of previous experiences of discrimination, abuse and segregation. People with learning disabilities are more likely to have experienced physical, emotional or sexual abuse as children and young adults, and will carry the legacies of these experiences into their own parenting experiences.

Some professionals have raised concerns that parents with learning disabilities experience undiagnosed mental health problems, including post-natal depression, and argued that it is important to diagnose and respond to such needs (see discussion in Cotson et al, 2001, pp. 291-292).

Professionals consulted for this guidance raised their concerns that physical health problems experienced by parents with learning disabilities are also sometimes undiagnosed.

The presence or absence of social support would seem to be more important than the presence or absence of learning disability in terms of the implications for parenting capacity. Social support and stress are negatively correlated amongst mothers with learning disabilities, "suggesting that the former may buffer the adverse effects of the latter" (Feldman et al, 2002). The larger, more recent and more helpful the support network reported by mothers with learning disabilities, the better their psychological wellbeing and the greater likelihood of positive parenting experiences (Kroese, et al, 2002).

[5] This and other quotes from parents with learning disabilities, come from meetings held with parents as part of putting together this good practice guidance.

Learning disability may also mean that a parent has some specific support needs relating to their impairment.

There is no clear relationship between IQ and parenting, unless it is less than 60 (McGaw and Newman, 2005). However, although IQ is not a good indicator of parenting capacity, cognitive impairment may mean that a parent has difficulty with reading and writing, remembering and understanding, decision-making and problem-solving, and this will create particular support needs.

Indeed, most parents with these difficulties recognise that they need practical support and help with learning about child care (Tarleton et al, 2006). Parents who came to a National Gathering of parents with learning disabilities emphasised, for example, that they need information in accessible formats:

> "The information given to parents in booklets like 'Birth to 5'[6] isn't accessible to parents with learning disabilities. We need information in pictures, plain English, and on tape" (CHANGE, 2005, p.17).

Parents' learning disability can also impact on their children's development in that, for example, their own language difficulties may inhibit their ability to stimulate their children's language development.

This may mean they need advice about verbal interaction with children and/or additional support to children to help with language development (Cotson et al, 2001, pp.290-291).

Children's experiences

We know very little about the experiences of children of parents with learning disabilities, other than that which concerns their parents' experiences of children's social care and the child protection system. A study of assessments of families affected by parental learning disability found that half the children had severe developmental needs and two-thirds were experiencing family and environmental disadvantages (Cleaver and Nicholson, 2007).

One 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";

[6] This booklet, published by the Department of Health in 2005 was given to all new parents. CHANGE have produced a series of accessible books for parents with learning disabilities; see Resources section for details.

- 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; 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), were consulted as part of drawing up this practice guidance. They 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".

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 young people 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."

The Commission for Social Care Inspection consulted 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).

The role of the extended family

The role of the extended family is particularly important for parents with learning disabilities (Tarleton et al, 2006). A survey of people with learning disabilities in England found that those who had children were more likely to still be living with them if they were also living with other relatives. This was particularly the case for mothers – nine out of ten of mothers living with other relatives still had their children with them, compared to only four out of ten who lived in their own households.[7]

McGaw and Newman conclude, from their survey of what works with parents with learning disabilities, that: "The importance of family ties should be recognised and no actions taken that damage such ties" (McGaw and Newman, 2005, p.59).

[7] These figures were provided by Eric Emerson in a secondary analysis of data from Emerson et al. 2005

Extended family members may also 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, there is also evidence that kinship carers are likely to experience greater economic difficulties and poorer accommodation than non-kin foster carers (see Broad 2005). Some grandparents have reported that they are not only incurring costs of looking after their grandchildren but are also providing continuing financial support to their adult children" (Social Care Institute for Excellence, 2006).

However, 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 (Tarleton et al, 2006, p.64).

Risk and child protection issues

Learning disability is not correlated to deliberate abuse of children: "…IQ by itself, is not a predictor either of the occurrence or of the non-occurrence of purposeful child abuse…" (Tymchuck, 1992, p.168). Most concerns about children's welfare where parents have learning disabilities relate to inadequate levels of childcare and, when children are recorded on the child protection register, it is usually under the neglect or emotional abuse categories. This is "neglect by omission [and] is a result of a lack of parental education combined with the unavailability of supportive services" (Cleaver and Nicolson, 2007).

Even then, however, it would appear that learning disability is not the decisive factor. Recent research, which looked at 101 parents in contact with a learning disability parenting service, found that IQ of the main parent-carer was not correlated with risk of child protection concerns.

On the other hand, 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 (McGaw et al, 2010).

Where children's social care remove children from the care of families affected by parental learning disability, there are usually other difficulties faced by parents, in addition to learning disability. These include mental health and/or physical health problems, domestic violence, substance abuse, isolation from family and friends, poverty and inadequate housing (Cleaver and Nicholson, 2007; see also Brophy, 2006).

The experiences of adults' and children's social care when responding to families affected by parental learning disability

Research has highlighted the difficulties that both children's and adults' social care experience when responding to the needs of families affected by parental learning disability.

Children's social care experience a number of barriers in their work with families affected by parental learning disability

Children whose parents have learning disabilities account for only a small proportion of all children referred to children's social care, and, as a study pointed out, "it would, therefore, be unrealistic to expect social workers from children and family teams to have the expertise and specialist skills needed to work with people with learning disabilities" (Cleaver and Nicholson, 2007).

Nevertheless, this study of children of parents with learning disabilities, whose welfare was of concern to children's social care, found "little evidence of social workers in children and family teams making use of professionals with specialist skills in working with people with learning disabilities or taking advantage of relevant tool kits or questionnaires and scales aimed at assessing parenting skills" (Cleaver and Nicholson, 2007).

> *"They explain things in words you don't understand and you think help I don't understand what she's saying and you ask her to say it again and she uses the same language and I feel really stupid because I still don't understand but I don't feel I can ask her to say it again".*[8]

This study also found that parents with learning disabilities are less likely than other parents to approach children's social care for help. Those who come to the attention of children's social care exhibit higher levels of family, environmental and child development problems than families unaffected by parental learning disability. In most cases, families were also experiencing other difficulties, such as poor mental and physical health, domestic violence, substance abuse, or the impact of having grown up in care. Many of the parents were also bringing up a disabled child.

The study challenged the idea that children of parents with learning disabilities are removed precipitately by children's social care: only 17% of the sample was removed over the three year period of the study and removal only followed a range of service provision.

However, the researchers also conclude that there was very little evidence of on-going support to parents: most support provided was time-limited and short-term; most of the cases were closed but were then re-referred; and half the children who continued to live with their parents had their names placed on the child protection register during the three year follow-up period (Cleaver and Nicholson, 2007).

[8] Parent with learning disabilities participating in a group discussion carried out as part of preparing this guidance.

The difficulties that children's social care experience in delivering effective support to families affected by parental learning disability are reflected in the dissatisfaction with such interventions expressed by parents themselves. Parents with learning disabilities involved in another recent research project felt that children and families services:

- Did not understand people with learning disabilities
- Did not listen to them
- Expected them to fail
- Did not give them clear messages regarding what was expected of them
- Treated them differently from other parents who needed support
- Used their need for support, or any difficulties with their child, against them as evidence that they could not parent
- Used their previous history of having children removed, when they had not had adequate support, against them
- Provided no support once their children had been taken from them.

(Tarleton et al, 2006)

"Once my daughter went into foster care, I was told I couldn't carry on going to the Sure Start parenting group because she wasn't living with me. But nothing had been decided for definite then. I felt I wasn't being given a chance to do better."

Adult learning disability services also sometimes have difficulty in meeting the needs of parents with learning disabilities.

A survey of community learning disability nurses found they did not generally feel adequately prepared by their pre or post-basic training to support parents with learning disabilities (Culley and Genders, 1999). Although there has been an increase in the numbers of parents with learning disabilities receiving a service from community learning disability teams, there continues to be gaps in training (Tarleton et al, 2006).

Eligibility criteria for adult learning disability services often mean that parents with learning disabilities do not receive this service. For example, a study of a community learning disability team in an East London borough found that parents with IQ scores of 70-85 comprised a significant proportion of referrals but following assessment none were offered support or intervention in the medium to long term. At the same time, generic family support services were reported as inadequate to meet their needs (O'Hara and Martin, 2003).

There are considerable barriers to communication and collaboration between adult learning disability and children and family services.

There is much evidence of a lack of communication, co-operation and joint working across adult and children's services, and between health and social services, where a parent has a learning disability (e.g. Tarleton et al, 2006). There is also evidence of children and families social workers believing that adult learning disability services do not pay sufficient attention to children's welfare; and of adult learning disability services believing that children and families social workers have little understanding of the needs of parents with learning disabilities.

"The two sides don't talk to each other and we're stuck in the middle."

The problems arising from a lack of co-ordination between children's and adult services are exacerbated where parents with learning disabilities have additional mental health, substance abuse and domestic violence problems. Evidence from inspections indicates that those who come to the attention of children's social care were usually not known to adult learning disability services and, in any case "because the thresholds of these services were so high these parents were unlikely to receive support from them" (Department for Education and Skills, 2003, p27).

What do we know about what helps parents with learning disabilities and their children?

A National Gathering of over 200 parents with learning difficulties and those supporting them said these are the things that help people with learning difficulties be good parents:

- Accessible information about you and your baby's health, and about how to look after your baby
- Self-advocacy groups; coming together with other parents
- Getting support before things go wrong and become a crisis
- Being assessed in your own home, not in an unfamiliar residential family centre
- Assessment and support by people who understand about learning disabilities
- Advocacy
- Making courts more accessible
- Support for fathers
- Support for women and men experiencing violent relationships.

(CHANGE, 2005, pp.6-7)

There is considerable evidence that – for most parents experiencing problems - better parenting can be achieved if particular types of support, interventions and teaching methods are made

available (Lloyd, 1999; Moran et al 2004). This is just as true for parents with learning disabilities as it is for parents who do not have learning disabilities (McGaw and Newman, 2005).

However, support, interventions and teaching methods all need to be appropriate to parents' particular situation and learning requirements. Parenting support which is suitable for most parents is unlikely to be delivered in a way which is right for parents with learning disabilities:

> "Service providers need to be wary of the argument that all parents should be treated alike and offered the same services as the mainstream population. Empirical research and clinical practice indicate that the majority of services are as yet inadequate in meeting the needs of families that may need extra, specialised help" (McGaw and Newman, 2005, p.14).

It is also necessary to be wary of assuming that what is best for most parents with learning disabilities will be best for all. For example, while home-based interventions show the highest rates of improvement for most parents with learning disabilities, there are some parents for whom the home environment is not suitable, perhaps because they live with their parents or other family members who exert too much control over them to enable them to learn effectively (see the summary of research in SCIE, 2005).

What type of support is known to have good outcomes?

The following research findings have important implications for those planning and delivering services:

Self-directed learning can bring about long-term improvement in parenting skills

A Canadian learning disability service has been providing a parent education programme since 1981. Self-directed learning was developed to teach basic child care, 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).

Group education combined with home-based intervention is more effective than either home-based intervention or a group education programme on its own

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 (McGaw, Ball and Clark, 2002).

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, pp.35-36).

Parents with learning disabilities value both advocacy services and those which support self-advocacy

Advocates are particularly valued by parents with learning disabilities in helping them to address the environmental disadvantages they experience, such as inadequate housing; making information and communication accessible; and to develop self-esteem and self-confidence (CHANGE, 2005; Tarleton et al, 2006). An action research project found that both individual advocates and advocacy support groups were positively valued by parents and by professionals with whom they were in contact.

The following roles were provided by advocates:

- a witness to parents' dealings with officials and practitioners
- a buffer by fielding or deflecting matters that might exacerbate stress
- a voice making sure parents' views were heard
- a go-between improving links between families and services
- an interpreter putting information into language that parents could understand
- a listener enabling parents to talk things over
- a scribe helping with letters and forms
- a problem-solver helping families think things through
- a fixer sorting out problems of service delivery
- a conduit channelling the lessons learned in supporting one family for the benefit of another
- a sounding-board encouraging families to have confidence in their own ability to cope by helping them to work things out for themselves
- a confidante with whom confidential information could be safely shared
- an ally unambiguously on the family's side
- a sleuth tracking down and searching out information
- a mentor sharing general knowledge and experience
- an observer looking out for early signs of stress
- a mover and shaker making things happen.

(From Booth and Booth, 1998)

There would appear to be some key characteristics of successful interventions

A review of research on interventions with families affected by parental learning disability concluded that practitioners need to draw on a range of possible interventions in order to put together support needed by a particular family. It is also important that long-term support is available when needed (McGaw and Newman, 2005, p.47).

In addition:

- 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
- Other methods of engagement are needed long term
- 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 which 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.

(From McGaw and Newman, 2005, p.58).

Good co-ordination and communication between children's and adult services is key to effective interventions

A survey of research literature and examination of good practice concerning parents who have additional support needs generally (including parents with learning disabilities) 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.

(Social Care Institute for Excellence, 2006)

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

Best practice surveyed (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
- 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, on-going support where required and anticipating changes in needs in relation to both impairment/illness and family circumstances.

Conclusion

While there is evidence that families affected by parental learning disability experience a range of difficulties, it is also clear that most parents with learning disabilities are not receiving the type of support which is known to bring about improved outcomes for children.

Appendix B Policy and legal context

There have been some significant developments in government policy regarding children and families since 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 (the Care Act 2014 introducing the wellbeing principle, the Children and Families Act 2014 speeding up care proceedings and adoptions, for example), but the essential aims remain the same, namely early intervention with a view to securing family wellbeing.

Similarly, government's broad aims relating to disabled people remain unchanged, namely equality of rights and opportunities.

The original Appendix B in 2007 set out the then policy and legislative framework for both children's and adult services that provided the foundation for the features of good practice identified in the Good Practice Guidance. It is beyond the remit of this basic, interim update to provide full details of current government policy that support the good practice; only a broad outline is therefore provided, leaving the detail for a future, full refresh of the Guidance by the Department of Health.

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.
- 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.

(Department of Health, 2009, page 30)

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."
>
> (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

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."
>
> (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

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.

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. (The Munro Review of Child Protection, 2011)

Life Chances Strategy: improving the life chances of disadvantaged children and families – the Government outlined its strategy in the 2016 Queen's Speech and has confirmed that early intervention will play 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 the culture of 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 which can be used by all local agencies who are 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

(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.

Where children are at risk of experiencing significant harm, a key marker of good practice is that:

> "A broad range of integrated, evidence-based services are available to prevent children and young people from being harmed, safeguarding those who are likely to suffer significant harm, and address the needs of those children who have suffered harm, at the same time, providing support to their parents/carers."
>
> (Department of Health and Department for Education and Skills, 2004a, p.146)

Supporting People is also 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 Act 2002** places a duty on housing authorities to work with other agencies to tackle and prevent homelessness. Parents and children may have entitlements to help with accommodation if they cannot stay where they are living because of violence, or they are staying with family/friends, or they cannot live with all members of their normal households in their current accommodation, or their current housing conditions are damaging their health.

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.

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 2015 (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 difficulties, 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 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 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 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.

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 6.102 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. https://www.gov.uk/guidance/care-and-support-statutory-guidance

Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children (2015) (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 2007 Good Practice Guidance at Appendix C, Further Sources of Information, where there is a hyperlink to the archived document.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/419595/Working_Together_to_Safeguard_Children.pdf

The **2010** version of Working Together 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 via the hyperlink below.) Reference was made to the 2007 Good Practice Guidance in footnotes and hyperlinked in the References section. http://webarchive.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/publications/eorderingdownload/00305-2010dom-en-v3.pdf

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).

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.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306282/Statutory_guidance_on_court_orders_and_pre-proceedings.pdf

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.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/441643/Children_Act_Guidance_2015.pdf

Case law examples

Parenting with support

Re D (A Child) (No 3) Finding the Right Support (2006) Tarleton, Ward and Howarth http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/rightsupport.pdf 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 a 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.* http://www.bailii.org/ew/cases/EWFC/HCJ/2016/1.html

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 in 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 address parents' needs arising from their disability which might impact adversely on their parenting capacity. Joint training needed for adult and children's services.* **Re G and A (Care Order: Freeing Order: Parents with a Learning Disability) [2006] NIFam 8.**

Failure to apply the Good Practice Guidance

Recent cases in the 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.* http://www.bailii.org/ew/cases/EWFC/OJ/2015/B66.html

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.*
http://www.bailii.org/ew/cases/EWHC/Fam/2011/402.html

Assessments

Targeted and suitable expert assessments are required. **Re C [2014] EWCA Civ 128**

Communication

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. **Derbyshire County Council and SH [2015] EWFC B102**

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

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

Fair processes

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

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

Joint working

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. **Re S [2013] EWCA Civ 1073**

Conducting proceedings where there is a learning disability

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

Parental responsibility

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

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. (Working Together 2015, chapter 1)

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 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"
>
> (Children Act 1989, section 17).

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 2015.

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.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/419595/Working_Together_to_Safeguard_Children.pdf.

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"
>
> (Department of Health et al, 2000, Paragraph 3.58)

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. 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 but should always be evaluated to demonstrate the impact they are having on the outcomes for the child.
(Working Together 2015, page 15)

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.

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).
(Working Together 2015)

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.

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 (Children Act 1989, section 47).

Detailed statutory guidance about managing individual cases is set out in chapter 1, Working Together (2015) 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 (Children Act 1989, section 43).

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 (Working Together 2015, page 41).

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.
(Working Together 2015, page 41)

The overall aim of a child protection plan is to:

- 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.

(Working Together 2015, page 45).

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).
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

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, 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, Calls Landing, 4th Floor, 36–38 The Calls, Leeds LS2 7EW. info@changepeople.org Tel. 0113 242 6619; Fax. 0113 242 6142; www.changepeople.org.uk

Mencap – provides Accessible Communication and Easy Read Services, including training. For information and advice about these services, contact Mencap Tel. 0808 808 1111; help@mencap.org

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.

The British Standards Institution (BSI) has developed guidance on commissioning accessible websites. The new British standard on web accessibility, published in November 2010, builds upon the 2006 publicly available specification 'Guide to Good Practice in Commissioning Accessible Websites' (PAS 78). **BS 8878 Web accessibility. Code of Practice** is applicable to all public and private organisations wishing to offer accessible, usable websites to their customers. Contact BSI Customer Services Tel. 0845 086 9001 or by email at cservices@bsigroup.com.

Photosymbols
Photosymbols are a popular set of pictures for making easy read information for people with a learning disability. Subscription needed. http://www.photosymbols.com/

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. www.scie.org.uk

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:

Stockport Social Services and Stockport NHS Foundation Trust: Care Pathway for Pregnant Women with Learning Disabilities. For information, contact: Denise Monks denise.monks@stockport.gov.uk

Essex County Council Practice Guidance: Referral and Joint Working Arrangements for working with parents and carers who have a learning disability. For information contact: Kate Evans, Service Manager, Family Centre and Family Group Conferences, kate.evans@essexcc.gov.uk or kate.evans@raineronline.org

Norfolk County Council Enabling parents with a disability or long-term illness: Joint Policy and Protocol.
http://www.norfolkparents.org.uk/img/files/disabled_parents_protocol_oct_2011._ncc082406.pdf

Cornwall Working together to support parents with a learning disability: an inter-agency protocol for Cornwall. The principles from 'Think Child, Think Parent, Think Family' are embedded within the guidelines. This whole family approach requires adult and child services to work together to offer co-ordinated support to help families, overcome challenges and work towards positive outcomes for parents and their children.
http://www.cornwallfoundationtrust.nhs.uk/DocumentsLibrary/CornwallFoundationTrust/OurServices/ChildrenAndYoungPeople/SupprtedParentsProtocolLeaflet.pdf

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 can get better support. www.wtpn.co.uk

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 from http://www.bild.org.uk/information/useful-resources/learning-disabilities-to-other-areas/.

Enabling Parenting with Support: Effective working with parents with learning disabilities. CHINN. A training pack. Pavilion Publishing and Media Ltd 2012.

4. Assessment tools

Parent Assessment Manual by Sue McGaw, Kerry Keckley, Nicola Connolly and Katherine Ball. http://www.pillcreekpublishing.com/sue_mcgaw.html

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. http://www.norfolklscb.org/wp-content/uploads/2015/09/Corrected-Learning-Curves.pdf

Parenting Assessments for parents with learning difficulties – guidance from the Working Together with Parents Network http://www.bristol.ac.uk/sps/wtpn/resources/

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

5. Person centred planning

The Foundation for People with Learning Disabilities provides a number of resources relating to person centred planning.
http://www.learningdisabilities.org.uk/?view=Search+results&search=person+centred+planning

See also Circles Network
http://www.circlesnetwork.org.uk/index.asp?slevel=0z114z116&parent_id=116

6. Parenting skills resources

The London Network for Parents with Learning Disabilities Information and advice for parents with learning disabilities in London. http://www.londonparents.net/index.html

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, Calls Landing, 4th Floor, 36-38 The Calls, Leeds LS2 7EW. info@changepeople.org; Tel. 0113 242 6619; Fax. 0113 242 6142; www.changepeople.org.uk

BILD publications:
I want to be a good parent – Five illustrated cards to help parents carry out a range of essential child care tasks. For use with support from health or child care 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

Both available from: BILD Publications, BookSource, 50 Cambuslang Road, Cambuslang, Glasgow G32 8NB. http://www.booksource.net/contact-us or www.bild.org.uk/our-services/books

7. Legal proceedings

The Court and Your Child. When social workers get involved. Accessible information for parents available free from CHANGE. www.changepeople.org.uk

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

Meeting the needs of vulnerable clients. Law Society Practice Note for solicitors. http://www.lawsociety.org.uk/support-services/advice/practice-notes/meeting-the-needs-of-vulnerable-clients-july-2015/

Appendix D Bibliography

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. and Booth, W. 2004. Parents with learning difficulties, child protection and the courts, www.supported-parenting.com/projects/NuffieldReport.pdf

Booth, T, Booth, W. and McConnell, D. 2005a. '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), pp.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

Broad, B. 2005. Kinship Care: CareKnowledge Briefing 14. www.careknowledge.com

Brophy, J. 2006. Research Review: Child care proceedings under the Children Act 1989, Department for Constitutional Affairs.

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.

Cleaver, H. and Nicholson, D. 2003. Learning disabled parents and the Framework for the Assessment of Children in Need and their Families, Unpublished interim report to the Department for Education and Skills.

Cleaver, H. and Nicholson, D. 2007 Children living with learning disabled parents. Report for the 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.

Cooke, P. 2005. ACTing to Support Parents with Learning Disabilities, Nottingham: Ann Craft Trust.

Culley, L. and Genders, N. 1999. 'Parenting by people with learning disabilities: the educational needs of the community nurse' Nurse Education Today, 19(6), pp. 502-508.

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 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.official-documents.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: http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf

Department of Health, 2002c. National Standards on the Provision of Children's Advocacy Services. www.dh.gov.uk/assetRoot/04/01/88/93/04018893.pdf

Department of Health, 2002d. 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 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

Emerson, E, Malam, S, Davides, I and Spencer, K. 2005. Adults with Learning Difficulties in England 2003/4, www.ic.nhs.uk/pubs/learndiff2004

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, pp.314-323.

H M Government, 2015. Working Together to Safeguard Children: A guide to inter-agency working to safeguard the welfare of children. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/419595/Working_Together_to_Safeguard_Children.pdf

H M Government, 2006. Common Assessment Framework for Children and Young People: Practitioners' Guide. www.ecm.gov.uk/caf

H M Government, 2015.Information sharing: Advice for practitioners providing safeguarding services to children, young people, parents and carers. https://www.gov.uk/government/publications/safeguarding-practitioners-information-sharing-advice

HM Government, 2007.Statutory guidance on making arrangements to safeguard and promote the welfare of children under section 11 of the Children Act 2004. www.everychildmatters.gov.uk/safeguarding/

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 Disabilities15 (4), 324-340.

Lloyd, E, ed. 1999. What works in parenting education? Ilford: Barnardo's.

McGaw, S. and Newman, T. 2005. What works for parents with learning disabilities? Ilford: 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'.

Moran, P, Ghate, D, and van de Merwe, A. 2004. What works in parenting support? A review of the international evidence, London: Department for Education and Skills. www.prb.org.uk/wwiparenting/RR574.pdf

Morgan, P and Goff, A. 2004. Learning Curves: The Assessment of Parents with a Learning Disability, Norfolk Area Child Protection Committee.

Munro, 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/Munro-Review.pdf

Office for Disability Issues, 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

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, pp.18-24.

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

Social Services Inspectorate, A Jigsaw of Services: Supporting disabled adults in their parenting role, London: Department of Health.

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, pp. 165-178.

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/