


Good practice guidance on
working with parents with a
learning disability



--	--	--

Policy	Estates
HR / Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership Working

Document Purpose	Best Practice Guidance
ROCR Ref:	Gateway Ref: 7428
Title	Good Practice Guidance on Working with Parents with a Learning Disability
Author	DH and DfES
Publication Date	01 Jun 2007
Target Audience	NHS Trust CEs, Local Authority CEs, Directors of Adult SSs, Allied Health Professionals, Directors of Children's SSs
Circulation List	PCT CEs, Voluntary Organisations/NDPBs, Directors of Education/Children's Services
Description	Good practice guidance, including a summary of relevant legislation and policy, on how adult and children's services should work together to improve support to parents with a learning disability and their children.
Cross Ref	n/a
Superseded Docs	n/a
Action Required	n/a
Timing	None
Contact Details	Sally Hall-Demir Office of National Director: Learning Disabilities Wellington House 133-155 Waterloo Road London SE1 8UG 0207 972 4035 www.valuingpeople.org.uk
For Recipient's Use	

Foreword

We are delighted to be asked to provide a foreword to *'Good Practice Guidance on Working with Parents with a Learning Disability'*. This guidance sets out how children and adults' services can and should work together to improve support to parents with a learning disability.

Since the Valuing People White Paper in 2001 (DH), promoting the rights of people with learning disabilities has been a priority for this government. In the last six years there have been a number of policy initiatives and guidance documents aimed at improving the life opportunities for people with learning disabilities. This guidance follows in that spirit.

Being a parent is a huge responsibility, and this guidance is about supporting people with learning disabilities to care for their children so that they are safe and secure. The underpinning theme is that people with learning disabilities have the right to be supported in their parenting role, just as their children have the right to live in a safe and supportive environment.

We would urge those of you working within the health and social care fields to step up to the challenge to ensure that people with learning disabilities have the necessary support to *parent in a positive way*. Furthermore, we hope that this guidance sends out a clear message that people with learning disabilities can be good parents and can contribute meaningfully to the society in which they raise their children.



Ivan Lewis

Parliamentary Under-Secretary of State for Care Services

and



Parmjit Dhanda

Parliamentary Under Secretary of State for Children, Young People and Families

Good practice guidance on working with parents with learning disabilities

Contents

	Page
Acknowledgements	3
Introduction and Executive Summary	4
Section 1 Key features of good practice in working with parents with learning disabilities.....	6
Section 2 Good practice where safeguarding procedures are necessary	23
Section 3 Good practice in commissioning	30
Appendix A What do we know about the needs and circumstances of parents with learning disabilities?	35
Appendix B The policy and legislative framework	48
Appendix C Resources	57
Appendix D Bibliography	60

Acknowledgements

This good practice guidance followed a meeting between parents with learning disabilities and officials from the Department of Health, Department for Education and Skills and other government departments in 2006. The meeting had been arranged by Rob Greig, National Director, Learning Disabilities following a National Gathering of Parents with Learning Disabilities in January 2005. Thanks are due to parents who came to the meeting and also to the large number of parents who came to the National Gathering.

During the course of writing the practice guidance, I talked to parents in Camden, Bristol and Leeds. My thanks to those parents and also to Parents & Co, (Elfrida Rathbone Camden), Circles Network (Family Matters project, Bristol) and CHANGE for organising and supporting the meetings.

Joy Howard and Bradford Support Care provided me with valuable information about support foster care. Eric Emerson (Lancaster University) provided some useful secondary analysis of the national survey of people with learning disabilities.

The Special Parenting Service in Truro, Cornwall organised a meeting with children of parents with learning disabilities and I am very grateful to the children and to Debbie Valentine and Sarah Mundy who set up the meeting.

The following people advised the work and/or commented on earlier drafts:

Hedy Cleaver, Emeritus Professor, Royal Holloway College, University of London
Celia East, Safeguarding Manager, Suffolk County Council
Barbara Evans, ADSS Children and Families Committee
Jenny Gray, Children's Safeguarding Policy Unit, DfES
Rob Greig, National Director, Learning Disabilities
Joan Inglis, Project Manager, Support for Disabled Parents, Norfolk County Council
Helen Jermy, Learning Disability Locality Manager, West Berkshire
Sue McGaw, Debbie Valentine and Sarah Mundy, Special Parenting Service, Truro
Penny Morgan, Consultant Clinical Psychologist
Helen Tomkys, Social Care Directorate, Department of Health
Alison Woolley, NSPCC
Linda Ward, Director, Norah Fry Research Centre, University of Bristol.

Jenny Morris
April 2006.

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 and social care services, for all service providers and is for the information of Primary Care Trusts. 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 legislative framework 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:

- Fair Access to Care Services: Guidance on eligibility criteria for adult social care. Department of Health, 2002.
- Framework for the Assessment of Children in Need and their Families, Department of Health et al, 2000.
- Statutory guidance on Inter-agency co-operation to improve the well-being of children: Children's Trusts. HM Government, 2005.
- Working Together to Safeguard Children: A guide to multi-agency working to safeguard and promote the welfare of children, HM Government, 2006.
- Statutory guidance on making arrangements to safeguard and promote the welfare of children under section 11 of the Children Act 2004, HM Government 2007.

Why is this good practice guidance needed?

As the research summarised in Appendix A illustrates, practitioners often experience some difficulties supporting families are 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 are 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 parents' entitlements.

Whilst 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 disability discrimination legislation. This guidance will assist local authorities to fulfil their disability equality duty to promote 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 guidance:

Fair Access to Care Services: Guidance on eligibility criteria for adult social care. Department of Health, 2002.

Framework for the Assessment of Children in Need and their Families, Department of Health et al, 2000.

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

The following good practice guidance is also relevant:

The Common Assessment Framework for Children and Young People: Practitioners' Guide, HM Government, 2006.

What To Do If You're Worried A Child Is Being Abused. HM Government, 2006.

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

- Improve children's well being, in other words to enable them to:
 - Be healthy
 - Stay safe
 - Enjoy and achieve
 - Make a positive contribution
 - Achieve economic well-being.
- 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 Fair Access to Care Services
- Parents with learning disabilities are entitled to equal access to services, including parenting support and information services
- Public bodies have a duty to actively promote equality of opportunity for people with learning disabilities.

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.

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
- Information on tape and CD/DVD
- 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 people with learning disabilities.

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

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

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
- Be 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 4). 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 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 to (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 (2006) (see charts on pages 143 -147). 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 assessment:
- 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 covered 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, 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 meets monthly to offer support/advice to professionals/agencies that work with families where one or both parents may have learning difficulties. Professionals are offered a 'slot' at the meeting to present a case and the multi-agency team offer advice and, if necessary, appropriate referrals are made.

From Thetford Sure Start – for more information contact: Bridgitte Shad, Health Care Co-ordinator, bridgitte.shad@norwich-pct.nhs.uk.

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 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, unless there are concerns about children's welfare, in which case 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.

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.

Eligibility should not be determined by general exclusions or based on one type of criteria, such as IQ.

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 their 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 Fair Access to Care Services, paragraph 65). 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. Further details from: Joan Inglis, Project Manager, Support for Disabled Parents, joan.inglis@norfolk.gov.uk

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' entitlements to support under community care legislation, 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 promote good practice in assessment by using appropriate assessment materials and resources and/or access specialist expertise.

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, or a child in need assessment using the Framework for the Assessment of Children in Need and their Families, 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, 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 and the Framework for the Assessment of Children in Need and their Families 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).

Good practice in assessment of parents with learning disabilities

The Framework for the Assessment of Children in Need and their Families, 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 community care 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 Disability Discrimination Act 1995).

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 are 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 covered in Section 3.

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 of learning disabilities may be more likely to be bullied and their parents may have less 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 example²

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.

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

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.

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 mindset 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 learnt 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

A twenty one year old mother became pregnant. She lived on her own, her husband having left her. She had a learning disability and her previous child had been permanently removed from her care. She was alienated from her extended family. The initial plan was to apply for a court order to remove the child at birth but attempts were made to examine any other possible options.

It was decided to explore the possibility of placing the mother with a carer on the Adult Placement scheme. The aim was to provide the woman with a supportive environment where she could improve her life skills and then provide a safe environment for the baby where the mother could be helped to provide adequate care. An adult carer was identified and the mother moved in prior to the baby's birth. The intention is that this is a long-term placement which will continue for as long as the mother and child require such support.

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.

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 with 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 confidence to state their needs. Advocacy may also be necessary if a parent is to give informed consent in respect of a service intervention.

1.5.3 Independent advocacy should always be provided where children are the subject of a child protection plan and/or care proceedings instituted.

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) as these are not always readily available.

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.

<http://www.everychildmatters.gov.uk/workingtogether/>

Information Sharing: Practitioners' Guide.

<http://www.everychildmatters.gov.uk/resources-and-practice/IG00065/>

Protocol on Advice and Advocacy for Parents (Child Protection)

<http://www.dh.gov.uk/assetRoot/04/01/89/00/04018900.pdf>

National Standards on the Provision of Children's Advocacy Services.

<http://www.dh.gov.uk/assetRoot/04/01/88/93/04018893.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 legislative basis for action and the entitlement of parents to support under both children's and community 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 community 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 2.2.5 and 2.2.9 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 Disability Discrimination Acts 1995 and 2005) to ensure that the children of parents of 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 have a right to a private and family life, but children 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.

Where formal independent advocacy is not available, parents should be encouraged to involve a friend, relative or member of their local community to support them through the process.

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, 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 need to be protected from harm. Specialist input to assess and meet the needs of a vulnerable adult may be required.

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 fully participate.

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 parents' '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

A voluntary organisation, specialising in supporting people with learning disabilities, was asked to undertake a community-based assessment of a mother with a two year old son. Her previous experiences of services and the pending care proceedings meant “she was finding it impossible to engage with professionals she regarded as patronising, judgemental and unreliable”. The organisation developed a “mutually respectful relationship” with her and “together we were able to identify several areas where appropriate support would significantly improve her parenting skills”. The assessment resulted in 10 hours of support per week being provided for three months and the date of the final court hearing was put back to accommodate this. At the end of this period, parenting capacity was assessed as having improved sufficiently to mean that her child should remain with her. The voluntary organisation will continue to visit once a week.

Taken from Circles Network Annual Report 2003-2004

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 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 people with learning disabilities 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, under Fair Access to Care Services. 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.

Arrangements for developing such a strategy will depend on local arrangements for commissioning adult learning disability services and local Children's and Young People's Plans. The principles for commissioning are set out in the National Service Framework for Children, Young People and Maternity Services (Department of Health/Department for Education and Skills, 2004a, pp. 112-3). A framework for joint planning and commissioning has also been published: Joint Planning and Commissioning Framework for Children, Young People and Maternity Services, 2006, www.everychildmatters.gov.uk/_files/312A353A9CB391262BAF14CC7C1592F8.pdf. The Department for Education and Skills has published a number of resources for commissioners <http://www.everychildmatters.gov.uk/strategy/planningandcommissioning/>.

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.

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 an 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 need and ways of meeting such needs. It is helpful if commissioning strategies include proposals for 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.

Section 31 of the Health Act 1999 makes possible the pooling of health and local authority resources to meet the needs of a particular population group. 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. See also,
www.everychildmatters.gov.uk/strategy/planningandcommissioning/poolingbudgets/

3.3 Developing services

3.3.1 The development of services should be underpinned by the principles and aims of both Valuing People and Every Child Matters.

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 ‘well-being’ for all children in their area by enabling children to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Have economic well-being.

Children’s services authorities also have a duty to reduce inequalities in well-being 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.

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 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.

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 the frameworks and criteria 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 which will be required as part of the Disability Equality Duty, so that local authorities can assess whether they are fulfilling their duty to promote 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 disability equality duty, as required in the Disability Discrimination Act 2005 (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 know very little about the experiences of fathers with learning disabilities.

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 request 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, 2004) There are also varying estimates of the proportion of parents whose children are removed from their care. It would appear, from of a recent national survey of people with learning disabilities, that about 40% of parents are not living with their children³. 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 18⁴.

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.

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, forthcoming). 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, forthcoming). 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.

“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, forthcoming).

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).

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.

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 well-being and the greater likelihood of positive parenting experiences (Kroese, et al, 2002).

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 recent 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, forthcoming).

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”;
- 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;

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

- 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). The recent 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 households⁷. 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).

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, forthcoming).

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, forthcoming). 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, forthcoming; see also Brophy, 2006).

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

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

Recent 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 recent 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, forthcoming). 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, forthcoming).

"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, forthcoming).

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

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

- 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 parent's 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 enhance
- 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 that adult services have a 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, ongoing 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 legislative framework

This Appendix sets out the policy and legislative framework for both children's and adult services. This framework provides the foundation for the features of good practice identified in the good practice guidance. Policy documents, legislation and guidance are **highlighted**.

We first set out the policy framework for supporting parents with learning disabilities and their children, and this is then followed by summaries of the legislation and guidance.

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

Government policy is set out in Green and White Papers and National Service Frameworks. Two key aspects of the current policy framework 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 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).

For children and parents generally, the policy aim, set out in ***Every Child Matters: Change for Children***, 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 well-being.

www.everychildmatters.gov.uk/aims/

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 well-being 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. Three initiatives are intended to help achieve this:

The **Common Assessment Framework** (CAF) is to help people in contact with children (particularly those in universal services) identify any additional needs children may have if they are to achieve the five Every Child Matters outcomes (see www.everychildmatters.gov.uk/deliveringservices/caf/). It also aims to improve multi-agency working by providing a clear process for a holistic assessment of a child's needs, taking account of the individual, their family and their community. All local authority areas are expected to implement the CAF between April 2006 and the end of 2008.

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 (see www.everychildmatters.gov.uk/leadprofessional/).

Contact Point will be the quick way to find out who else is working with a child or young person and allow services to contact one another more efficiently. This basic online directory will be available to authorized staff who need it to do their jobs. It will hold basic information on every child, including the name and contact details for the general practice where they receive primary health care, the school they attend and contact details of practitioners working with the child. Contact Point will not contain any detailed information (such as case notes, assessments, clinical data or exam results). The legal framework for the operation of Contact Point will be provided by Regulations made under section 12 of the Children Act 2004. Currently, information sharing is supported by practice guidance for practitioners.
<http://www.everychildmatters.gov.uk/deliveringservices/informationsharing/>

The **Integrated Children's System** (ICS) is a framework for working to improve the outcomes for children in need. All local authorities are expected have an electronic system to support the use of the Integrated Children's System. This means that children's social care staff are using electronic case records routinely to help them in their work. This is intended to help managers and practitioners collect, use and share information systematically and effectively.
(see www.everychildmatters.gov.uk/ics/)

The **National Service Framework for Children, Young People and Maternity Services** recognises 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 well-being 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.

The legislative framework for supporting parents with learning disabilities and their children

Legislation and guidance set out the responsibilities of organisations and the rights of individuals. The legislation and guidance for supporting parents with learning disabilities and their children is described below under two main headings: the responsibilities of adult social care; the responsibilities of children's social care.

It is also important to recognise that all the services referred to below – from the provision of information, assessment, the putting in place of services to meet assessed need, to action taken to protect a child from significant harm – are covered by Part 3 of the **Disability Discrimination Act 1995**. This requires service providers to make 'reasonable adjustments' to ensure that a disabled person receives the same level of service as a non-disabled person.

In addition, both adult services and children's services authorities have a duty to promote equality of opportunity for disabled people (including parents) in their local population (Disability Discrimination Act 2005). This means that they should take pro-active steps to ensure equal access and equal treatment. This applies to all their functions, from drawing up Children and Young People Plans, commissioning services, assessments through to service provision.

1. The responsibilities of adult social care

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

1.1 Information

The **Chronically Sick and Disabled Persons Act 1970**, Section 1(2) 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, they must provide information about other sources of support and advice.

The **Disability Discrimination Act 1995**, Part 3 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 **Disability Discrimination Act 2005** places a responsibility on public bodies to ensure that disabled people generally have equal access to their services (including the provision of information).

1.2 Assistance with daily living

Adult community care legislation and guidance lays down a framework for the assessment and meeting of needs for assistance with daily living.

Adults who come within the definition of disabled person within community care legislation, or who "appear to be in need of community care services" are entitled to an assessment of their needs (**Disabled Persons Act 1986**, Section 4; **NHS and Community Care Act 1990**, Section 47(1)).

LAC(93)10 set out clearly that, when assessing whether someone is eligible for community care services, councils have a general duty not to 'fetter their discretion' and to consider each individual's circumstances (Department of Health 1993) This has been confirmed by subsequent case law. Operating blanket policies in community care services would breach the duty to assess an individual's need for services. General exclusions using a particular level of IQ, for example, are unlawful.

Policy guidance, **Fair Access to Care Services**, on how assessments should be carried out states that they should be “rounded and person-centred” and take into account housing, health and other needs (Department of Health, 2002a, Paragraph 35) . The assessment should include what support is required in order to fulfil family roles and responsibilities. The assessor should recognise that “individuals are the experts on their own situation and encourage a partnership approach to assessment” (Ibid). During the assessment process, the person being assessed should be given every opportunity to express their views and, if necessary, assistance (such as an advocate) should be provided to enable them to do this (Ibid).

Fair Access to Care Services also sets out the framework for determining eligibility. Family roles and responsibilities must be taken into account in all four eligibility levels set out in the guidance. In determining eligibility, for example, ‘critical’ level includes: “vital family and other social roles and responsibilities cannot or will not be undertaken”; while ‘substantial’ level includes: “the majority of family and other social roles and responsibilities cannot or will not be undertaken” (Department of Health, 2002a, Paragraph 16).

When determining eligibility, social care should take into account any risks in both the short and the long-term to the ability to carry out family roles and responsibilities. This consideration should cover not only risks to a parent not being able to fulfil their parenting roles, but also risks to children and other family members and carers. Adult social care are therefore required to take into account the possible effects of not meeting levels of need which currently do not qualify (as ‘critical’ or ‘substantial’ for example): “The council should have satisfied itself that needs would not significantly worsen or increase in the foreseeable future for the lack of help, and thereby compromise key aspects of independence, including involvement in...parenting responsibilities” (Ibid. Paragraph 65).

If adult social care decide that someone is eligible for help a care plan must be written showing how any eligible needs will be met. Services/direct payments should be provided in good time to prevent problems arising.

Fairer Charging Policies Guidance requires that assessments of whether someone should pay anything towards the cost of a service/direct payment should be accompanied by welfare benefits advice, and should include help with completion of benefit claims and follow-up action (Department of Health, 2003b).

1.3 Adult social care responsibilities concerning children

When responding to a referral for community 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 in accordance with the **Framework for the Assessment of Children in Need and their Families** (Department of Health et al, 2000, Paragraph 5.11).

The **Children Act 1989** places a general duty on local authorities to safeguard and promote the welfare of children. **Fair Access to Care Services** affirms this by requiring adult social care to address their duty to safeguard and promote the welfare of children when determining eligibility for adult community care services. “Where appropriate, councils should consider the use of the **Framework for the Assessment of Children in Need and their Families** to explore whether there are any issues relating to children in need and their parenting. The Assessment Framework should be used if it appears that there are children in need. On occasions, within one family, it may be necessary to concurrently assess the needs of an adult parent using the appropriate format for adult assessment, and the needs of the children and related parenting issues using the Assessment Framework” (Department of Health, 2002a, Paragraph 9).

1.4 Direct payments

Direct payments guidance states that, where someone has been assessed as having eligible needs for support, direct payments must be offered as an alternative to services to anyone “who appears to the council to be able to manage them (either alone or with help)” (Department of Health, 2003a, paragraph 47). Payments can be made directly to the person who needs the assistance, or to someone who will manage the payments on their behalf (paragraph 42).

The guidance also states that “Councils should not make blanket assumptions that whole groups of people will or will not be capable of managing direct payments” and that any judgements about whether someone is capable of using a direct payment should “be made on an individual basis, taking into account the views of the individual and the help that may be available to him or her. Where an individual does not agree with the council’s judgement, they should have access to advocacy and, if available, arbitration, to ensure that their arguments are properly considered, or access to the council’s complaints procedure” (paragraph 48).

The guidance stresses that “Councils should ensure that needs assessments for disabled adults include parenting responsibilities” (paragraph 113) and that direct payments can also be given in lieu of services provided under the Children Act 1989: “In the interest of the family and to avoid duplication, local councils should ensure the assessment process is streamlined and coordinated between adult and children’s services and other relevant departments such as education” (paragraph 114). **Fair Access to Care Services Practice Guidance** states that “It will be important for children and family teams to have agreed policies and protocols with adult teams” on how to respond to the needs of families where the parent is disabled (Department of Health, 2002d, p.10).

Advice and support services should be available to assist a person to decide whether they want direct payments and to provide any help they may need in using them (Ibid., paragraphs 24-35). These support services should be accessible, taking into account particular needs of people with learning disabilities (paragraph 31) and advocacy services should also be available for those who need them in order to use direct payments (paragraph 36).

If a person is receiving at least £200 week (or the equivalent in services) from their local council, and they receive the higher rate of Disability Living Allowance care component, they can apply to the Independent Living Fund for a grant to meet any additional needs that they have for personal assistance. However, this cannot include assistance with parenting tasks.

1.5 Housing

Housing needs should be covered in a community care assessment and, if appropriate, adult social care should involve the housing authority in the assessment and care plan (**NHS and Community Care Act 1990**, Section 47(3)). 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 (**Homelessness Act, 2002**).

Households with a disabled adult or a disabled child may be entitled to assistance with adaptations to their property, through both the **Disabled Facilities Grant** system and the **Chronically Sick and Disabled Persons Act 1970**. A guide on housing adaptations sets out the relevant legislation and guidance, and recommends good practice (Office of the Deputy Prime Minister, 2004).

2 The responsibilities of children's services

2.1 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 **Disability Discrimination Act 1995**, Part 3 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 **Disability Discrimination Act 2005** 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).

2.2 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 **Framework for Assessment of Children in Need and their Families**. 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.

(Department of Health et al, 2000)

This 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)

In these kinds of situations, the statutory guidance says children's social care should:

- "Recognise the cumulative effect of lower levels of needs;
- Ensure a high degree of co-operation and co-ordination between staff in different agencies;
- Take extra care to ensure that "there is an holistic view of the child and that the child does not become lost between the agencies involved and their different systems and procedures."

(Department of Health et al, 2000, Paragraph 3.59)

The guidance also stresses that children “should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances” and where there is a danger of this happening, “services should be provided to parents to enhance their ability to fulfil their parenting responsibilities” (paragraph 3.62). Children and young people who are taking on a caring role are entitled to an assessment under section 1(1) of the **Carers (Recognition and Services) Act 1995** and this assessment must be taken into account when a decision is made about what services to provide to the parent. Children’s social care should consider whether a child’s welfare or development might suffer if support is not provided to the child or family. “Services should be provided to promote the health and development of young carers while not undermining the parent “ (Department of Health et al, 2000, paragraph 3.63).

Where parents have particular needs relating to learning disability (and/or mental health or other specific needs), a specialist assessment may need to be commissioned while carrying out an assessment using the **Framework for the Assessment of Children in Need and their Families** (Department of Health et al, 2000, paragraphs 5.36, 6.18-6.22)

Where a child is assessed as being in need of services in order to attain a reasonable standard of health and development, a Child in Need plan should be drawn up, with the agreement of the child and key family members, detailing the services to be put in place and the aims to be achieved (Ibid., paragraphs. 4.32-4.37). The objectives should be “reasonable and timescales not too short or unachievable”; and the plan should not “be dependent on resources which are known to be scarce or unavailable” (Paragraph 4.34).

Direct payments can be made to parents and to 16 and 17 year olds, in lieu of services provided under Section 17 of the Children Act 1989 (as amended by the **Health and Social Care Act 2001**, Section 58).

2.3 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 5 of **Working Together to Safeguard Children** (HM Government, 2006). 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 (HM Government, 2006, Paragraph 5.51). Where parents/caregivers are unwilling to co-operate with an assessment, the court can be asked to grant a Child Assessment Order (HM Government, 2006, Paragraph 5.68).

An initial assessment should be carried out using the guidance in the **Framework for the Assessment of Children in Need and their Families**. If there is reasonable cause to assume that a child is suffering, or at risk of, significant harm and section 47 enquiries are initiated, a strategy discussion must be held to decide if section 47 enquiries should be undertaken. A core assessment is the means by which the section 47 enquiry will be carried out, involving all relevant agencies.

Core assessments under section 47 of the Children Act 1989 should:

- “Build a picture of the child’s situation using information from a range of sources
- Always involve separate interviews with the child (as long as their age/understanding allows this)
- Usually involve interviews with parents/caregivers, and observation of the interactions between parents and child(ren)
- Include interviews with those who are personally or professionally connected with the child and parents/caregivers
- Draw on assessments by other professionals”

(HM Government, 2006, paragraph 5.62).

The guidance also makes clear that “Individuals should always be enabled to participate fully in the enquiry process. Where a child or parent is disabled, it may be necessary to provide help with communication to enable the child or parent to express him/herself to the best of his or her ability”; and “If the child is unable to take part in an interview because of age or understanding, alternative means of understanding the child’s wishes or feelings should be used, including observation where children are very young or where they have communication impairments” (HM Government, 2006, paragraph 5.63).

Where it is decided that the child is not at risk, or is not at continuing risk, of significant harm, children’s social care and other relevant agencies should always consider whether services are required to prevent problems arising in the future (HM Government, 2006, paragraph 5.73)

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. 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.

The overall aim of a child protection plan is to:

- “Ensure the child is safe and prevent him or her from suffering further harm
- Promote the child’s health and development i.e. his or her welfare
- Provided it is in the best interests of the child, to support the family and wider family members to safeguard and promote the welfare of their child”

(HM Government, 2006, paragraph 5.124).

The 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).

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, Units 19/20, Unity Business Centre, 26 Roundhay Road, Leeds LS7 1AB.

info@changepeople.co.uk Tel. 0113 243 0202; Fax. 0113 242 0220.

www.changepeople.co.uk

Mencap

Mencap's Accessibility Unit publishes a guide on writing accessible documents: 'Am I making myself clear?' www.mencap.org.uk/download/making_myself_clear.pdf

Mencap can edit documents or write accessible documents. This involves writing in plain language, adding pictures and images to support the text and looking at layout and design. They also produce scripts, record audio tapes and offer training on producing accessible documents.

Tel. 020 7696 5551

accessibility@mencap.org.uk

www.mencap.org.uk/html/accessibility/accessibility_services.asp

Making websites accessible

Since October 1999 website owners have had a legal duty under the Disability Discrimination Act 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. Publicly Available Specification (PAS) 78 is available from BSI Customer Services on 020 8996 9001 and by email at orders@bsi-global.com. It costs £30.00 plus VAT and is available in the following alternative formats: braille, easy read, accessible PDF, large print, audio, DAISY and Welsh.

Mencap publishes a guide on making websites accessible to people with learning disability.

www.mencap.org.uk/download/webaccess.pdf

2. Joint protocols and care pathways: good practice examples

In 2007 the Social Care Institute for Excellence will be publishing 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 will include a protocol template. www.scie.org.uk

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

Stockport Primary Care Trust, 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

See also, Commissioning Strategy for Parents with a Learning Disabilities.

For information contact: Steve Bailey, Participation Development Manager, Steve.Bailey@essexcc.gov.uk

Norfolk County Council

Enabling parents with a disability or long-term illness: Joint Policy and Protocol.

The protocol is on the Valuing People Support Team website:

<http://valuingpeople.gov.uk/dynamic/valuingpeople115.jsp>

For information contact:

Joan Inglis, Project Manager, Support for Disabled Parents, joan.inglis@norfolk.gov.uk

3. Resources for working with parents with learning disabilities

The **Working Together with Parents Network** is a network of:

- Parents and carers with learning disabilities
- Professionals working with people with learning disabilities
- Statutory and voluntary organisations
- Other individuals or organisations with an interest in the area.

The Network aims to spread positive practice and to promote policy change, so that parents with learning disabilities and their children can get better support.

<http://www.bris.ac.uk/norahfry/right-support/>

The **Valuing People** website has a section on parents with learning disabilities and contains a number of resources and useful links: <http://valuingpeople.gov.uk/dynamic/valuingpeople115.jsp>

4. Assessment Tools

Parent Assessment Manual by Sue McGaw, Kerry Keckley, Nicola Connolly and Katherine Ball.
www.cornwall.nhs.uk/specialparentingservices/patientassessmentmanual.asp

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.

Learning Curves can be downloaded from the Norfolk LSCB website, free of charge, www.acpc.norfolk.gov.uk. A4 wirebound paper copies are available from: Paul Shreeve (Norfolk LSCB Administrator), The Pineapple, 63 Bracondale, Norwich NR1 2EE (The cost is £8 including postage- cheques made payable to Norfolk County Council.)

5. Person Centred Planning

The **Valuing People Support Team** has a website devoted to person centred planning:
<http://www.valuingpeople.gov.uk/pcp.htm>

Circles Network also provides a number of resources related to person centred planning:
http://www.circlesnetwork.org.uk/what_is_person_centred_planning.htm

6. Parenting Skills Resources

CHANGE publications:

Planning a Baby booklet

You and Your Baby 0-1: a practical handbook for parents with learning disabilities to have at home for them to read.

For more information contact Frances Affleck or Philipa Bragman at CHANGE (contact details above)

BILD publications:

I want to be a good parent 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 health and warm

Children need to be safe

Children need love

Both available from:

BILD Publications, BookSource, 32 Finlas Street, Cowlairs Estate, Glasgow G22 5DU
08702 402 182

<http://www.bild.org.uk/03books.htm>

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.

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. forthcoming. *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, 2002a. *Fair Access to Care Services: Policy Guidance*, London: Department of Health. www.dh.gov.uk/assetRoot/04/01/96/41/04019641.pdf

Department of Health, 2002b. *Fair Access to Care Services: Practice Guidance*, London: Department of Health.
www.dh.gov.uk/assetRoot/04/01/97/34/04019734.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, 2003a. *Direct Payments Guidance: Community care, services for carers and children's services (direct payments) guidance*, England, London: Department of Health.
<http://195.33.102.76/assetRoot/04/06/92/62/04069262.pdf>

Department of Health, 2003b. *Fairer Charging Policies for Home Care and other Non-Residential Social Services*, London: Department of Health.
www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/FairerChargingPolicies/fs/en

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, 2005. *Statutory guidance on Inter-agency co-operation to improve the well-being of children: Children's Trusts*. www.everychildmatters.gov.uk/strategy/guidance/

H M Government, 2006. *Working Together to Safeguard Children: A guide to inter-agency working to safeguard the welfare of children*. <http://www.everychildmatters.gov.uk/workingtogether/>

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

H M Government, 2006. *Information sharing; Practitioners' Guide*. www.ecm.gov.uk/deliveringservices/informationsharing/

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 well-being of mothers with intellectual disabilities' *Journal of Applied Research in Intellectual Disabilities* 15 (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. forthcoming. '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.

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.