

Contents

Acknowledgements		4
Introduction and Executive Summary		5
Section 1	Key features of good practice in working with parents with learning disabilities	
Summary		8
Main section		10
Section 2	Good practice where child protection procedures are necessary	
Summary		33
Main section		35
Section 3	Good practice in commissioning	
Summary		45
Main section		46
Appendix A	What do we mean by people with learning disabilities?	53
Appendix B	What do we know about the needs and circumstances of parents with learning disabilities?	55
Appendix C	Legislation and Policy Framework	67
Appendix D	Resources	79
Appendix E	Bibliography	84

Acknowledgements

These good practice guidelines are a product of two events. As part of the UK wide Working Together With Parents Network, a group of practitioners and parents started meeting together in 2006. Early on they recognised the need for guidelines to encourage more consistency of good practice.

Then in 2007 “Good practice guidance on working with parents with a learning disability” was published by the Department of Health and the Department of Education and Skills. This guidance applied to England, and was based on English law, policy and services. Nevertheless, it was seen as a blueprint for what was needed in Scotland.

Thanks to funding from the Baring Foundation, the Esmee Fairbairn Foundation and the Scottish Government, we were able to produce these Scottish Good Practice Guidelines that take full account of Scottish legislation, policy and services.

These Guidelines borrow heavily from the English guidance, written by Jenny Morris on behalf of the Department of Health and the Department for Education and Skills.

The Legislation and Policy Section was written by Susan Hunter and Janice McGee, Senior Lecturers in Social Work at Edinburgh University.

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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
- Increase the chances of avoiding family breakdown which has enormous social and financial consequences.

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

Why is this good practice guidance needed?

Where a parent has a learning disability it is 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.

This is the reality for many parents with learning disabilities. Many experience poverty and unemployment, poor housing and difficult neighbourhoods, and lack of information. Harassment and bullying, and sometimes violence and financial or sexual exploitation, can be a major problem for parents with learning disabilities and their children. Many need ongoing support to care for their children. However, the support needed is not always provided. Having a learning disability in itself is not a reliable indicator of poor parenting, yet high numbers of parents with learning disabilities have their children removed (see Appendix B).

A Life Like Any Other? (Joint Committee on Human Rights, 2008) highlights the experiences of parents with learning disabilities. It says "Unless justified as a proportionate and necessary response to a risk to the child, ... compulsory removal of a child from the care of its parents poses a significant infringement of the rights of both the child and its parents, to respect for their family life" (page 59). It is hoped that these Guidelines will assist practitioners to provide the information, arrangements and supports that parents need to allow them to demonstrate that they can look after their children satisfactorily.

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

- Children whose parents have learning disabilities and who are in contact with children's social work services have high levels of needs
- Many parents with learning disabilities are not receiving the type of support which is known to bring about improved outcomes for children.

Children's services practitioners and adult learning disability workers do not always have a good working knowledge of the policy and legislative framework within which each other are working. Appendix C 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.

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. However, 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.

Appendix A gives a working definition of 'people with learning disabilities'. It also outlines what sorts of services are needed to support effectively people with learning disabilities. Appendix B summarises the research evidence, while Appendix C 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 C, in particular:

Getting it right for every child: Proposals for Action: Section 3

<http://www.scotland.gov.uk/Publications/2005/07/25112327/23294>

A Guide to Getting it right for every child

<http://www.scotland.gov.uk/Publications/2008/09/22091734/0>

Working Together to Support Disabled Parents

<http://www.scie.org.uk/publications/guides/guide19/files/guide19.pdf>

Getting it Right for Every Child: The Approach in Practice

<http://www.scotland.gov.uk/Resource/Doc/238985/0065824.pdf>

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.

How will it help?

As well as showing how to bring about better outcomes for parents with learning disabilities and their children, this guidance will assist public bodies in fulfilling their obligations under the Disability Equality Duty. This legislation places a responsibility on public bodies to promote equality of opportunity between disabled persons and other persons. This includes:

- encouraging participation by disabled persons in public life
- taking steps to take account of disabled persons' disabilities, even where that involves treating disabled persons more favourably than other persons.

These Guidelines will assist public bodies to comply with this duty 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. Key components of this compliance will be the availability of accessible information and the involvement of parents in the planning of services.

Throughout this document there are examples of good practice. Examples concerning individual families are anonymised descriptions of cases provided by some of the services consulted with for this good practice guidance. Quotations come from parents involved in preparatory meetings or at the consultation stage for these Guidelines, or for the equivalent English Guidance.

Section 1 – Key features of good practice in working with parents with learning disabilities

Summary

The main aim of good practice in supporting parents with learning disabilities and their families is to improve children's well being.

Accessible information and communication

- Services for parents and children should make information and communication accessible to parents with learning disabilities
- This includes health services and schools
- Parents need to be given information in a way that makes it easy to understand, and they need it in enough time
- Adult learning disability services should make sure parents know about their entitlements to assessments of need. They should also make sure parents know about support that is available to them
- Children and Families Services should also let parents know what support is available to parents, and give them information about their responsibilities as parents
- Assessments, care plans and other written information should be provided in accessible formats, and supported to understand it if necessary
- Information and communication should also be accessible to children

Coordinated Work

- The different agencies that should be involved in support families where parents have learning disabilities, should have joint local agreements about referrals, assessments and care pathways
- There should also be joint agreements about commissioning services
- Attention should be paid to promoting good communication between agencies
- Identification of needs should start when a pregnancy is confirmed
- Adult and children's social work teams should jointly agree referral procedures to prevent parents and children falling between the two departments
- Assessments should consider each family's needs and circumstances. Eligibility should not be based on whether a family is in crisis: an early response from services may prevent avoidable difficulties arising
- Local agreements should clearly specify responsibilities for assessment and care planning
- Services should promote good practice in assessment by using appropriate assessment materials and resources and/or access to specialist expertise

Support should be based on assessments of parents' needs and strengths

- Support should be suited to parents' learning needs and circumstances
- Support should be put in place at as early a stage as possible
- A family-centred approach should be taken to parenting support, responding to the needs of all family members, including parents and children
- A range of services are required, from all services sectors
- Support should be available (where needed) through all stages of the child's life
- A consistent and coordinated approach should be taken when more than one agency is involved
- Children should be provided with support in their own right
- Parents emotional needs should be recognised as support needs

Long term support

- A need for long term support does not mean that parents cannot look after their children
- Where there is a need for long term support, it should form part of the community care plan
- Practitioners should aim to build relationships where parents feel able to ask for support as needs change

Access to independent advocacy

- People with learning disabilities have a right to access independent advocacy
- Parents should have access to both collective self-advocacy and individual advocacy
- Commissioning strategies should address the availability of local independent advocacy
- Independent advocacy and self-advocacy should be made available to help parents access and engage with services
- Independent advocacy should always be provided where children are the subject of a child protection plan and/or children's hearings

Section 1 – Key features of good practice in working with parents with learning disabilities

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

Getting it right for every child: Proposals for Action: Section 3

<http://www.scotland.gov.uk/Publications/2005/07/25112327/23294>

A Guide to Getting it right for every child

<http://www.scotland.gov.uk/Publications/2008/09/22091734/0>

Working Together to Support Disabled Parents

<http://www.scie.org.uk/publications/guides/guide19/files/guide19.pdf>

The main aim of good practice in supporting parents with learning disabilities and their families is to improve children's well being. Specifically, this means to enable them to be:

- safe
- healthy
- active
- nurtured
- achieving
- respected
- responsible
- included

A second, and connected aim, is to 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 C (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 Children's Hearings 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
- 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 acknowledges any impairments, but also recognises the disabling barriers of unequal access and negative attitudes.

Such an approach places the focus 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). This allows 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

Good communication is vital in helping parents have as much control as possible. It helps families engage with services, and it helps services understand what each family wants and needs. Without good communication, families feel powerless and frustrated. Accessible information is part of providing good communication.

All services for parents and children should provide information that is clear and easy to understand. They should make it available in a number of different formats for example:

- Easy Read
- CD or DVD
- Large print
- Accessible websites
- Face to face meetings with people
- Support from an advocate to help with any of the above.

It is important to remember that everyone is different. Some parents might want a spoken conversation because they can't read. For others a spoken conversation alone would not help because they don't have good memories. Having a range of options is best. Where there is a range of options, parents need to know about this.

It is also important to give parents information when they need it. For example, it is not appropriate to give parents minutes from a previous meeting as they arrive for the next one. They might need support from a support worker or advocate to consider it, they might need support to prepare a response, or they might simply need time to go through the minute carefully.

Good communication requires much more than providing accessible information. Spoken communication is notoriously unreliable. Many parents find meetings difficult and stressful. They report that they don't understand what is happening at the time, and sometimes do not know what decisions have been taken.

Good practice example

A multi-disciplinary team in NHS Fife produced Easy Read versions of all their ante-natal written material. This material was piloted in NHS Fife and NHS Lothian: midwives used this written material with expecting mothers who had learning disabilities, and found that it greatly increased the quality of the communication.

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

Accessible information should be available at all stages of parenthood. This should start with sex education materials at school. These need to be accessible and available.

Written information and publications given to pregnant mothers should be made available in Easy Read format.

Some written information is given to new parents through NHS Scotland. This information should be made available in Easy Read format and given to all new parents with learning difficulties as a matter of course.

Good practice example

You and Your Baby is a parenting book that is given free of charge to all new parents in England. CHANGE produced an Easy Read version of this book. In Scotland, NHS Health Scotland have made this Easy Read version available to all Health Boards free of charge to use with the parents they are in contact with. They are currently monitoring the uptake of this resource, to see if it is meeting the needs of parents in Scotland.

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 fulfill such responsibilities unless information and communication is made accessible by teachers and schools. Schools need to take account of the communication needs of parents who have learning disabilities. Written information that is given to parents should be accessible. Parents' evenings should allow for some appointment times to be longer. Support with homework should also be available.

*"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." **

Other universal services for children and parents should provide accessible information. Services commissioned by health boards, local government or central government should insist as a condition of funding that information is provided in different accessible formats.

Training in producing accessible information and in communicating in a more accessible way is available from a number of organisations. See Appendix D for more details.

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.

Services for parents should provide accessible information about themselves. Adult learning disability services are well-placed to provide new parents and parents-to-be who have learning disabilities with this 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 work 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.

Parents can have a role in supporting and encouraging each other to request support and take up services. Therefore, self-help groups for parents should be promoted and encouraged by adult services.

**Quotations given are from parents with learning disabilities*

1.1.4 Children and Families services 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 and Families teams 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 Children and Families teams 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.

“Asking for support from the same organisation that takes your kids away is always going to be difficult”

(SCLD, 2008, p.6)

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:

- Explain things clearly so you really understand
- Make sure you understand reports
- Take time to communicate with us
- Ask us what we need and want
- Tell us about independent advocacy
- Are honest if they can't do something
- Give us information in the format that we need (e.g. on tape) on time
- Don't use jargon
- Listen
- Turn up on time
- Give us a choice
- Follow things up – on time
- Treat us as individuals

(People First (Scotland) Parents' Group)

Assessments should only be done with informed consent, unless required by the Courts/ Children's Hearings. Parents should therefore be given information – in a format suitable to them – about why an assessment is being carried out, what it will involve, and what might happen as a result. During and after an assessment a parent should be supported to understand what the assessment says.

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

Sometimes information is given and communication happens in meetings involving a number of professionals (such as child protection conferences: see also Section 2). It is important to make information and communication accessible in this context as well. Meetings can be very disempowering for parents. Jargon should be avoided and parents should have someone to support them to prepare for the meeting and take part in it, if this is what they want. Parents with learning disabilities have the right to access independent advocacy (see Section 1.5) An independent advocate could support parents in this way.

"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. 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 coordinated referrals and assessments, prioritisation and care pathways

The steps in to a service could be: a referral (including self-referral), an assessment, a decision about providing support, and a care pathway that shows what professionals are involved and when.

Referral and assessment procedures, appropriate prioritisation 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 work services, 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.

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.

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 and Families services, others also include health and sometimes education and housing.

Whatever form a local protocol takes, the following issues should be included. These 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:
- Financial responsibilities, including provision for joint funding

- Charging
- Service provision, including joint working
- Service reviews
- Implementation of the protocol, including training
- The provision of independent advocacy

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
 - need for support to maintain 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 different departments are all over town: Education Department, Social Work Department, Children and Families. I see them to try and get my youngest into a pre-school programme. That was a nightmare – we got him a place but no-one would pay for the transport: Children and Families said it was Education, Education said it was Children and Families, so I would go from one building to another.

That was hard because I had to travel all over town. My memory's bad and I'm not good at finding my way around. I started making trails in the grass from the bus stop to the offices, so I could find my way back, but the birds started eating the trail! So I tried marking the trees instead.

Then what happens is they change the structure or move offices, and don't tell us. Or if they do tell people it's written somewhere and I can't read it. So everything takes even longer to sort that out.”

(SCLD, 2008, p.5)

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 learning disability team; 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

When Amanda was pregnant for the second time, the Children and Families Team was ready to take the newborn child into care, as had happened the first time. But ENABLE Scotland made a proposal to offer day to day support, based on an agreed Action Plan, and liaise regularly with the Children and Families Team. This arrangement, based on an agreed way of working with clearly outlined roles, has worked well, with the child remaining with her parents and doing well.

(summary of account, SCLD, 2008, p.14)

Professionals could learn directly from the experience of parents in the matter of what practices are effective. Training and consultancy on how to do this effectively is available from a number of organisations (see Appendix D).

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 work services. 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 that:

- 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 the support that is needed to look after a new baby will help to prevent avoidable difficulties arising.

Good practice example

NHS Fife's Unborn Child Policy encourages early information sharing between practitioners and family where planning is required to support ongoing 'good' parenting

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

It is good practice that, as a general rule, referrals relating to the needs of parents with learning disabilities should be directed to Adult Learning Disability Teams, unless there are concerns about children's welfare, in which case a referral should also be made to Children and Families Teams. 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 the Adult Learning Disability team for an assessment.

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.

1.2.5 Assessment for children's and for adult services should enable each family's needs and circumstances to be considered. Eligibility should not be based on whether a family is in crisis: an early response from services may prevent avoidable difficulties arising.

Many people with learning disabilities would not be considered eligible for services, and would not need them while they are responsible only for themselves. When they become parents their support needs increase, but even then may not be enough of a priority to get any support. In situations like this, children may have support needs, and parents have their own support needs as well. Of course, the support given to parents will have positive outcomes for the children.

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

Developing joint agreements will require services 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 will mean that their children's welfare suffers and they may 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. 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.

Parents should be involved in drawing up local protocols.

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

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

Good practice is promoted where there is clear agreement between adult and children's services 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 the entitlements to support that parents with learning disabilities have under community care legislation. They should ensure that they receive the assessment and service response they are entitled to.

Good practice example

In Paisley, Renfrewshire, there is a close working relationship between Renfrewshire Learning Disability Service (which is a joint working team comprising of health and social work), and the Family Matters Project. Family Matters is a service which provides support to vulnerable families with children under the age of 5 years. There are several individuals working for Family Matters with a specific interest in the difficulties experienced by parents who have learning disabilities.

There have been excellent joint working practices for several years now between nursing, social work and midwifery staff from Family Matters and the Clinical Psychologist from the Learning Disability Service. All referrals for parenting assessments are generally undertaken by at least one professional from each organisation, ensuring that information is shared and there is a breadth of practical and theoretical experience contributing to the process. The results from the Clinical Psychology assessment are shared with Family Matters, who then work closely with Clinical Psychology in order to provide teaching and support in child care to the individual, which is appropriate to their needs and abilities. Both of these organisations in turn work closely with the local area Child and Family Social Work Team to ensure a comprehensive assessment is carried out, with the aim of providing maximum support to each individual which is person-centred and appropriate to their abilities.

1.2.7 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. This means that a range of professionals who are in contact with children may need to consider the possibility of parental learning disability and its impact on children. Children and Families teams 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.

Parents themselves should be involved in identifying what support they need. This element of self-assessment should play a significant part in the overall assessment. For it to be effective there needs to be a strong degree of trust between the assessor and the parent(s). This is an important point, given the fear that some parents have of social workers.

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.”

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. However, Single Shared Assessments have been criticized for not being user friendly.

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. Assessments should take place in the family home, unless the home environment is actually disempowering to the parents. Assessments should also take account of the parents’ support needs, but also of other supports that are available e.g. extended family. 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.

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 Appendix D).

Assessments need to be reviewed as parents' needs change. Not only will parenting ability change over time, but needs and circumstances of the child(ren) will change.

Good practice in assessment of parents with learning disabilities.

Here is a checklist of good practice when assessing parents with a learning disability:

Assessors should be knowledgeable about both their statutory responsibilities, and about parents' legal rights, including their entitlements under community care legislation.

Where it is thought the parent has a learning disability, an initial screening tool should be used in order to determine whether a specialist assessment is required (see Appendix D).

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.

The purpose of the initial assessment should be to assess the parent's support needs. Parents should be reassured that this is the case.

Parenting assessments should be made at home 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.

Assessors must take the parents' communication needs into account. For example, a parent may need to be reminded what happened at the last meeting.

Parents should be actively involved in their own assessment

Independent advocacy is involved

Parents' support needs that are due to their impairment should be met before an assessment is carried out (in line with SCIE guidance)

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

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

Assessors should be aware that previous experiences may create significant fear about the role of children's social work 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 it is thought that the parent has a learning disability.

1.3 Support should be designed to meet the needs of parents and children, and should be 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)

Again, a number of voluntary sector organisations have the capacity to support parents in this way.

Parents with learning disabilities may need support to attend training event. Training should not replace good, flexible, ongoing support.

1.3.2 Support should be put in place at as early a stage as possible.

In many cases it is medical staff (e.g. GPs and midwives) who identify a parent with learning disabilities who may need support. Good communication between these health professionals and social work is very important for ensuring that this happens.

Community Learning Disability Teams are in a good position to offer appropriate early support, because of their multi-disciplinary nature.

Other support could be made available that does not require to be accessed through social work. Voluntary organisations and self-help groups can offer good early support, and parents with learning disabilities might feel more confident about approaching them for support. The availability of this kind of support should be well advertised.

Good Practice Example

Following a high risk pregnancy protocol referral, East Ayrshire Council recognised that the mother also required protection in terms of the Multi-Agency Adult's With Incapacity Procedures. Immediate steps were taken across disciplines and agencies to ensure that the pre-birth assessment was carried out by the most appropriate worker. This was a team manager from the learning disability team who already had an established, positive relationship with the mother. Steps were taken to streamline procedures to ensure that the mother could participate effectively in the process. Child protection and adult protection procedures were combined as 'family protection'.

Ultimately, a welfare guardianship was required to ensure that the care plan was provided to the mother on a statutory basis before the child's birth. The Council also amended existing procedures for high risk pregnancies on a multi-agency basis (including health, criminal justice, children and families and learning disability services). This revised process has been depicted as a flow chart which is currently being incorporated in all other relevant procedures including multi-agency Child Protection procedures as well as internal procedures such as GOPR.

1.3.3 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.

1.3.4 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 self-directed support 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
- Child care including nursery placements and Sitter services
- Support foster care/shared care
- Short breaks services.
- Support for the whole family

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.

It is possible that a number of workers from different agencies will be involved with a family. In situations like this it is important to be clear with parents about the role of each worker. Where a social worker is monitoring parents' behaviour to assess there are child protection issues, they should make this clear. Where workers are supporting parents to learn parenting skills, they should make this clear. Establishing trust is the basis of most progress, and this clarity of roles will help with this.

It is important that workers from different agencies show respect to each other, and for each other's roles. This will help build up the idea of a team supporting a family together.

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”.

1.3.5 Support services should be available to help parents to promote their child’s welfare throughout all stages of the child’s life.

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.”

1.3.6 Where a number of different agencies are involved in supporting families affected by parental learning disability, a consistent and coordinated 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.

It can help to have one lead support professional who has responsibility for the consistency of the support that the parent receives.

Good practice example

The Care Programme Approach (CPA) provides a framework for assessment and planning for individuals with complex and changing needs. In Fife, it has been used to support some parents with learning disabilities. This has been effective in raising awareness of the particular needs of these parents, especially for Children's Services professionals who may have no firsthand experience or knowledge of learning disability.

The CPA meeting not only helps areas of particular need to be identified, but also provides a forum where, for example, Speech and Language Therapy, Nursing and Psychology practitioners can offer guidance regarding appropriate ways of providing parents with information, and educating them in essential parenting skills. This helps to eliminate wasted effort and focuses professionals' interventions into more productive avenues.

The CPA also has the advantage of allocating essential tasks to named individuals. This helps to ensure agreed actions are carried out. The fact that the CPA document is recorded and monitored serves to identify gaps in services by highlighting unmet needs. Parents themselves seem to appreciate having a meeting which focuses on their needs as opposed to purely their children's, which is often how child centred meetings seem to individuals.

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

The children of parents with learning disabilities may need support in their own right. For example, their health or developmental needs may suffer while their parent is learning to better meet these needs and/or parent support services are being put in place.

Children, particularly older children, may be at risk of taking on inappropriate caring roles within the family, or their welfare may be threatened by inadequate parental supervision. In such situations, children will meet the 'child in need' criteria and adult and children's services should work together to address children's needs, while at the same time work is done with parents to increase their capacity to meet their children's needs. Neither intervention is a substitute for the other but should be provided in tandem.

Good practice example

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.

(Department of Health et al., 2007, p19)

1.3.8 Parents may need emotional support.

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

Parents may particularly need emotional support when Children and Families services 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, advocates and self-advocacy groups. Attitudes that parents might have towards social workers might make it appropriate for this support to be provided by someone independent of social work departments. Again all the different workers should be transparent about their role.

Key messages from parents

- **Don't pre-judge us**
- **Believe that we can change if we get the right support**
- **Recognise when we do things well and make changes**
- **We need time to build up trust so we can open up**
- **Independent support is easier to trust than social work because of the fear that social workers will take your children away**
- **Continuity is very important so we can get to know and trust you**
- **On-going, long-term support is often what we need**
- **Make sure you know what current support is out there in our local area, including independent advocacy**
- **Listen to our children**
- **Listen to what the whole family needs**
- **Help us understand how the system works**

People First (Scotland) Parents' Group

1.4. Long-term support should be available 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.

Long term support needs are a reality for some people with learning disabilities. Just as some people will need long term support to maintain a tenancy, some parents will need long term support with their parenting responsibilities.

Although a parent's skills and confidence may grow over time, any impairment they have will not go away. In addition, parental challenges change over time as children grow up and move into new phases of their own lives such as teething, learning to talk, going to school, puberty etc. A common parental experience is that, just as they feel they have got on top of one challenge, another presents itself. With each of these new phases, a parent with learning disabilities may require different support.

1.4.2 Where a need for long-term support with parenting tasks is identified, it should form part of the community care 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.

More information about this scheme on: <http://www.naaps.org.uk/en/shared-lives-membership/?PHPSESSID=863e5372ad6ba2ac6922bf9591e6cb0e>

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

Social work services and others who provide support to parents should aim for consistent and long-standing relationships with parents, which are trusting and mutually respectful. This will make it easier for parents to ask for and accept new support as their needs change.

The voluntary sector and community organisations have a good track record of providing these long-standing relationships. The availability of this kind of support would be one useful way of supporting parents in a way that builds up trust and addresses the problem of parents being fearful of social workers.

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

People with learning disabilities have a right to access independent advocacy under the Mental Health Care and Treatment (Scotland) Act (2003).

It is important that parents are supported to access independent advocacy if they want or need to at the earliest possible stage. Independent advocacy can help parents make better informed choices, can help them say what they want to say, and can help them achieve something they want to achieve e.g. access to a mainstream parenting group.

Parents should have access to both self-advocacy and individual advocacy. Self-advocacy groups help build people's confidence, which has many positive benefits to parents. Parents can share information, discuss common issues and practice what they want to say and how they want to say it. Collective advocacy allows groups of parents to speak with the power of a collective voice to bring about change in agencies that are not serving them well.

Individual advocacy can help parents say what they want to say, and can help them to follow through on decisions they have taken.

Independent advocates can help parents address many of the issues that they have to deal with: accessing support from social work, understanding what benefits are available, securing suitable housing, negotiating meetings with the children's school. For many parents these issues are regular and ongoing. Citizen advocacy is a model of long-term advocacy that allows a long term advocate to get to know the family and build up relationships with the parents. For other parents long term advocates are not needed, but wanted in occasional times of crisis.

Advocacy is not a substitute for accessible information. However, even in situations where information is provided in accessible formats, independent advocates can play an important role in supporting parents to understand information they are given, and to make decisions on the basis of that information.

1.5.1 Commissioning strategies should address the availability of local independent advocacy (see Section 3) as these are not always readily available.

These strategies should reflect the advantages that a range of different advocacy models can provide.

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

Parents with learning disabilities sometimes have a long history of difficult relationships with Children and Families services, 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 children's hearings.

Parents with learning disabilities should be supported to access independent advocacy at the earliest opportunity. Local authorities should not wait until the situation is critical.

However, any parent involved in a child protection conference and/or children's hearing proceedings who does not already have access to independent advocacy should now be supported to do this.

It is very important that parents have access to independent advocacy at an early stage. Relevant professionals, such as social workers, GPs, midwives and health visitors should all know what advocacy provision is available. It should be part of their agreements to refer parents where there is a concern about child protection.

Advocates should have appropriate skills and knowledge of both learning disability and child protection issues. Advocacy commissioners have a responsibility to provide advocacy organisations with enough capacity to develop the skills and knowledge of their advocates.

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

Section 2 - Good practice where child protection procedures are necessary

Summary

The main aim of good practice in supporting parents with learning disabilities and their families is to improve children's well being.

Promoting children's best interests

- Children have a right to be protected from harm, and for their interests to be paramount
- Children have the right to receive the necessary support so that, wherever possible they remain living with their parents
- Local authorities have a duty to ascertain the wishes and feelings of children when carrying out assessments and making decisions about service responses
- Where child protection 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 to prevent future problems arising
- Where a child protection case conference is convened, a child should be invited and supported to participate, subject to their age and understanding
- When a key worker is appointed for a child, it is important that the worker has some understanding of learning disability or, if not, that the worker has access to such expertise
- Children who are looked after or accommodated by a local authority should be entitled to independent advocacy
- Local authorities should promote contact with family members for children who are the subject of supervision requirements

Ensuring equitable treatment for parents with learning disabilities

- Parents have a right to family life, but children have a right to protection from harm
- Parents should be informed about their rights to legal representation and, where necessary, supported to access it
- Parents are entitled to access independent advocacy and should be supported, where necessary, to access it
- Independent advocates need to be skilled in supporting people with learning disabilities, and also have a good understanding of child protection measures
- Unless sharing information would place the child at risk of significant harm, parents should be informed about, and involved as much as possible in the whole process
- Assessments involving families affected by parental learning disability should always include specialist input concerning the impact of learning disability
- Where it is a partner (who may or may not have learning disabilities themselves) who poses a risk of harm to the child it will be important to support the other parent to protect the child
- Parents should be invited to attend child protection conferences and support should be provided to enable them to fully participate

Section 2 Good practice where child protection procedures are necessary

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

A guide to Getting it right for every child

www.scotland.gov.uk/Publications/2008/09/22091734/0

Getting it right for every child in Kinship and Foster Care

www.scotland.gov.uk/Publications/2007/12/03143704

Protecting Children: A Shared Responsibility Guidance on Inter-Agency Co-operation

www.scotland.gov.uk/library/documents-w3/pch-00.htm

Protecting Children and Young People: Framework for Standards

<http://www.scotland.gov.uk/Publications/2004/03/19102/34605>

It's everyone's job to make sure I'm alright

<http://www.scotland.gov.uk/Publications/2002/11/15820/14009>

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 to remain living with their parents, wherever possible.

2.1.1 Local authorities have a duty 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 child protection process, from the outcome of child protection enquiries through to Children's Hearing 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 child protection 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 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 compulsory intervention, 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 may also amount to a breach of the Human Rights Act 1998.

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). Any support plan drawn up should draw on the good practice identified in section 1 of these guidelines.

2.1.3 Where a child protection case 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 work services 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 looked after or accommodated by a local authority should be entitled to independent advocacy.

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

2.1.6 Local authorities should promote contact with family members for children who are the subject of supervision requirements, unless a children's hearing 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.

Where such difficulties arise families should be supported to use mediation services, legal and otherwise, that would be available to other families.

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.

The primary focus of support for families is on the welfare of the child. Research shows that children do best in their own families where that can be achieved. Therefore support should be thought of, wherever possible, as support for the family to keep the family together. This applies just as much when child protection measures are necessary.

When child protection procedures or referrals to the children's hearings are started, it is a very unsettling time for families. It is likely that parents will not know exactly what is happening, or what is likely to happen. It is possible they will be upset, anxious and stressed. Therefore, it is particularly important that communication at this time is effective, and it is important that parents have the support they need to understand what is happening, and also to say what they want to say during meetings.

Parents should be informed about their rights to legal representation and, where necessary, supported to access this.

Identifying solicitors who have an interest in this field and experience in representing people with learning disabilities would help ensure that parents' rights are upheld.

2.2.1 Independent Advocacy should be made available for parents at this point (see Section 1.5.3) This means that they are given the information and also, if necessary, supported to access it.

As well as the right to access advocacy under the Mental Health Care and Treatment (Scotland) Act, the Children's (Scotland) Act gives both parents and children the right to a supporter at children's hearings. This of course includes an advocate, and might also be friend, relative or member of their local community.

2.2.2 Independent advocates need to be skilled in supporting people with learning disabilities, and also have a good understanding of child protection procedures, and parents' rights within this context.

If parents choose to have informal supporters, these supporters should be provided with advice and information, or referred 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 child protection enquiries through to Children's Hearings.

Parents should be provided with information from health or social work in relation to their child, in an accessible format and, where necessary, supported to understand this information.

Parents attending should be sent guidance on what parents are entitled to before children's hearings.

Parents should be sent the same information as panel members ahead of the meetings.

They should be provided with whatever assistance may be required to enable them to understand what is happening and to express their views. A number of things might help with communication at meetings, such as Case Conferences:

- parents should have support with them, an independent advocate if requested
- members of the extended family could be an invaluable support to parents, and should be welcomed
- information about the meeting to be sent to parent in an accessible format and in good time (see section 1.1).
- pre-meeting with the Chair to explain the procedure of the meeting
- communication guidelines for meetings to follow
- a small core group to meet with parent afterwards to go through Child Protection Plans
- training for Child Protection committees in communicating with people with a learning disability
- parents to have child protection plans in an accessible format to keep with them
- ongoing support to remember and understand decisions that have been taken at meetings
- remember all parents are individuals and have different communication needs

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.

Parents should know about the timetables of the Children’s Hearing system. They should also be supported to understand how the system works and what is at stake at each meeting. Some parents have gone into meetings believing that the Children’s Hearing system was part of social work. Others have not fully understood what powers the Children’s Hearing has.

2.2.4 Assessments involving families affected by parental learning disability should always include specialist input concerning the impact of learning disability.

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.

It is important that all agencies work together on assessments and on developing care pathways after that. Each agency has its own areas of expertise, so it is important that this expertise can be shared across agencies. For example, if a Children and Families social worker is not skilled or experienced in communicating with people with learning disabilities, then a social worker from the Learning Disability Team, the parent's support worker or an independent advocate could help with communication.

2.2.5 Where it is a partner (who may or may not have learning disabilities themselves) who poses a risk of harm to the child it will be important to seek to support the other parent 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, in accordance with the Adult Support and Protection Act (Scotland) 2007.

2.2.6 Parents should be invited to attend child protection conferences and support should be provided to enable them to fully participate.

See 2.2.3 for a list of suggestions to make this process more inclusive for parents.

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)

Again, parents should be informed about their rights to legal representation and, where necessary, supported to access it.

2.2.7 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.

2.2.8 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.

2.2.9 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 patronizing, judgmental 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)

2.2.10 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 extremely stretched budgets in children’s social work services results in support being withdrawn at this point. This may mean that parents struggle to maintain improvements in their parenting capacity and they enter a ‘revolving door’ of re-referrals which may lead to 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. The importance of an assessment that identifies parenting support needs is crucial in this respect.

2.2.11 When children are placed in foster care, parents should receive practical support to maximize 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.

2.2.12 When children are placed in foster care, as long as continuing parental involvement is not considered detrimental to a child's welfare, this should be positively encouraged and promoted. 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)

2.2.13 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.

2.2.14 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.

2.2.15 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.

2.2.16 Children's hearings should be fully accessible in order to avoid discrimination against parents with learning disabilities.

One key issue for parents with learning disabilities involved in Children's Hearings 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. 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 fulfill 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 children's hearings looks at whether targets are creating obstacles to making reasonable adjustments for parents with learning disabilities.

2.2.17 Parents should have access to both emotional and practical support when the child protection process concludes with children being accommodated away from the family home.

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.

"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".

Good practice example

Galashiels Family Centre runs a group for parents with learning disabilities which includes parents that no longer have their child with them. They still appreciate the opportunity to be respected as a parent and to talk to staff about their child and their contact sessions. This provides workers with the opportunity to keep providing support, rather than having to end it when the child is placed.

Parents with learning disabilities should have the same access to post-adoption support as any other parents. Social workers should give parents information about what support is available, and make referrals where needed. These support organisations should provide information and support that is accessible to and appropriate for parents with a learning disability.

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 to be looked after by the local authority can be avoided if the necessary support is provided to people with learning disabilities. It will also be important to work with health colleagues to enable people with learning disabilities to have access to family planning and other health services.

Section 3 – Good practice in commissioning

Summary

- The main aim of good practice in supporting parents with learning disabilities and their families is to improve children's well being
- 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
- Parents should be involved at different stages of the process
- A commissioning strategy should be based on knowledge of current and likely future needs
- A commissioning strategy needs to be based on an audit of current service provision and an identification of the gaps in service provision
- Service user perspectives should inform the identification of need
- It is good practice to have formal joint commissioning arrangements
- The development of services should be underpinned by the principles and aims of both The same as you? and Getting it Right for Every Child
- Good practice in commissioning considers both the role of mainstream services and the development of a range of specialist services
- Service user perspectives should inform the development of both mainstream and specialist services
- Staff in both children's and adult services working with parents with learning disabilities will require training
- Services to parents with learning disabilities and their children should be monitored and reviewed using the frameworks and criteria operated by Learning Disability teams and children's services
- Statistical data on comparative outcomes can be supplemented by qualitative data in order to fully understand the reasons for any differences in outcomes
- Monitoring and reviewing of services should include the perspectives of service users

Section 3 – Good Practice in Commissioning

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

“The same as you? A review of services for people with learning disabilities”

<http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

Getting it Right for Every Child: The Approach in Practice

<http://www.scotland.gov.uk/Resource/Doc/238985/0065824.pdf>

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 work services in both the statutory and voluntary/independent sectors. All community planning agencies have a responsibility to provide effective supports.

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

In commissioning mainstream services and specialist services that parents with learning disabilities may benefit from, commissioners will be mindful of how they might fulfill their obligations under the Disability Equality Duty.

Parents should be involved at different stages of the commissioning process. Parents are well placed to identify gaps in provision, and to state what is needed and how this need might be met. But they also have an important part to play in defining the outcomes that families should expect from services, in service design, and in monitoring and evaluating existing services.

Local commissioning strategies should detail how parents will be involved.

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 and families services 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 work, 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. This audit should include an assessment of whether available mainstream services are accessible to parents with learning disabilities.

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 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.

Informal arrangements are too vulnerable to changes in personnel or changes in priorities.

Current legislation does not allow Adults' and Children's Services to pool their budgets. Nor does it allow pooling of budgets between social work departments and other agencies. However, formalized local agreements are likely to minimize the risk that families would fall between two stools – this is more likely to happen when funding responsibility is not clear-cut and there are competing priorities for funding.

3.3 Developing services

3.3.1 The development of services should be underpinned by the principles and aims of both *The same as you?* and *Getting It Right for Every Child*.

The same as you? laid out a direction for learning disability services to head. It affirmed the following underlying principles for services to base their work on:

- People with learning disabilities should be valued.
- People with learning disabilities are individual people
- People with learning disabilities should be asked about the services they need and involved in making choices about what they want
- People with learning disabilities should be helped and supported to do everything they are able to
- People with learning disabilities should be able to use the same local services as anyone else, wherever possible

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 work 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 services
- 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
- Self directed 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

Local Area Coordination is a role that exists now in most local authorities. LACs coordinate services and provide information and support. These are some of the main activities that LACs undertake (their role may differ from one area to another):

- Help people with learning disabilities decided what their needs are, and make plans for the future
- Provide information about specialist and mainstream resources in the area
- Build relationships with people with learning disabilities and their families
- Support people to develop and maintain strong networks
- Help people with learning disabilities to coordinate the way support and services are provided
- Make connections with members, groups and agencies from local communities

This type of role may be particularly helpful for supporting parents with learning disabilities when

- LACs work with whole families, not just parents or children
- It is a 'cradle to grave' service as is the case in some areas.

Good practice example

People First (Scotland) is a user led independent advocacy organisation that supports a self-advocacy group for parents. This group provides a place where parents can meet together, exchange information, support each other to advocate for themselves, and find a collective voice over a number of common issues.

Commissioning this resource is in line with The same as you? principles of having people with learning disabilities shaping and influencing their own services. The result is a resource which meets parents' needs, improves their self-confidence, and enhances their chances of promoting their children's well-being.

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 Staff in both children’s and adult services working with parents with learning disabilities will require training.

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 helpful if parents with learning disabilities are involved in delivering such training. The Resources section of this good practice guidance (Appendix D) 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 teams 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 to take steps to address this discrimination.

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 C).

Appendix A What do we mean by people with learning disabilities?

This Section is taken from **“The same as you? A review of services for people with learning disabilities”**

People with learning disabilities have a significant, lifelong condition that started before adulthood, which affected their development and which means they need help to:

- understand information;
- learn skills; and
- cope independently.

People with learning disabilities should have a range of support and services to meet the following needs.

Everyday needs

For example, a place to live, security, social and personal relationships, leisure, recreation and work opportunities.

Extra needs because of their learning disability

For example, help to understand information, support to make decisions and plan, learn skills, help with communication, mobility or personal care.

Complex needs

For example, needs arising from both learning disability and from other difficulties such as physical and sensory impairment, mental health problems or behavioural difficulties.

For any of these needs the level of support will vary. A person with learning disabilities may need:

- occasional or short-term support;
- limited support, for example, only during periods of change or crisis;
- regular long-term support, perhaps every day; or
- constant and highly intensive support if they have complex or other needs which are related.

As one person told us:

“You need to take time to get to know us — we are all different.”

So people with learning disabilities have a range of needs which will change during their lifetime. Professionals need to help people plan for the future. For many people with learning disabilities, particularly those with complex needs, organisations need to work together with the individual and their family to plan and support them.

People with learning disabilities should have the following.

- Services that promote and protect their health and welfare, help them lead lives which are as normal as possible and are best suited to their needs, whether at home, in schools, health services or other settings.
- Information, advice and help to get education, work and leisure that offers personal fulfilment, consistency and security, best meets their needs and personal preferences, and helps them to be included and accepted within local communities.
- Ordinary homes which are private, secure, comfortable and safe.

You can find further information and discussion about definitions in “The same as you? A review of services for people with learning disabilities”

<http://www.scotland.gov.uk/ldsr/docs/tsay-12.asp>

Appendix B 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.

'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 have a real and lifelong difficulty in learning things'.

In this book we have used the term 'people with learning disabilities'. It seems more appropriate to use this term because this is what is used within the legislation and statutory guidance for adult social work services. We do not say 'parents with a learning difficulty' because in education services 'learning difficulty' means something else.

However, we recognise that there is a risk in using the term 'learning disability'. One of the objections that people have to this term is that it can be taken to mean that people are not able to learn. This assumption has particularly dangerous implications for parents who may be facing a situation of having to prove that they can look after their children.

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. 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 work services, and it mostly concerns mothers. We know very little about the needs and experiences of such families 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 a recent national survey of people with learning disabilities, that about 40% of parents are not living with their children¹. 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 18².

Most parents with learning disabilities who are 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 and families services, 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 work services, therefore, often need to work with other agencies to attempt, for example, to improve a family's housing situation.

1 – Secondary analysis of data from Emerson et al, 2005

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

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

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 and families services also experience other difficulties such as **"poor mental and physical health, domestic violence, growing up in care, or substance misuse"** (Clever and Nicholson, 2005).

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.

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' 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 and families services and the child protection system.

A group of children of parents with learning disabilities (aged between 13 and 18), were consulted as part of drawing up the English Good 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."

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."

Similarly, a small study of children in Scotland found that bullying was a serious problem. All the children reported being targeted not just at school but in their homes (Miller 2008)

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 households³. 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”** (Clever and Nicolson, 2005).

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.

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

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 and families services 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, 2005; see also Brophy, 2006).

The experiences of adults' and children and families services 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 and families services 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 and families services, 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, 2005).

Nevertheless, this study of children of parents with learning disabilities, whose welfare was of concern to children and families services, 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, 2005).

"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".

This study also found that parents with learning disabilities are less likely than other parents to approach children and families services for help. Those who come to the attention of children and families services 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 and families services: 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 and families services experience in delivering effective support to families affected by parental learning disability are reflected in the dissatisfaction with such interventions expressed by parents themselves. Parents with learning disabilities involved in another recent research project felt that children and families services:

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

(Tarleton et al, 2006)

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

Adult learning disability services 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 services 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 and families services 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 the 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).

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 C Legislation and Policy Framework

There is a wide range of policy and legislation relevant to adults with learning disabilities across the public sector domains of health, housing, child care and adult care. General policy and legislative frameworks for all users of public services are also in place. In this section key elements of policy and legislation for adult and children's services have been drawn upon to identify aspects of relevance to parents with learning disabilities.

Adult services – policy and legal framework

The same as you? A review of services for people with learning disabilities (2002)

This review of services for people with learning disabilities (SAY?) was the first of its kind for twenty years. It made 29 recommendations focussing on social and health care and their interface with health, housing, employment and education. Just as importantly there was an explicit commitment to social inclusion through community based services, and during the life of the review the emphasis of the report shifted focus from one simply about services to questions of 'lifestyles' and quality of life.

In the words of the Minister,

**“That is what matters. Services are there to support people in their daily lives”
(Ministerial Foreword).**

He also makes reference to the importance of using direct payments, brokerage and advocacy in order to help people have more control and influence over their lives. Such options have particular relevance for parents with learning disabilities together with others noted below

* Recommendation 2: that local authorities and health should appoint local area co-ordinators (LACs) as from autumn 2001. LACs are intended to provide a focal point in the community for accessing person-centred support locally. The key feature is the provision of direct funding to individuals rather than block grants to services.

* Recommendation 3: 'personal life plans' should be put in place for everyone with a learning disability who wants one. Whilst those individuals with learning disabilities living with ageing parents figure prominently, the plans are intended to achieve longer-term planning so that individuals can lead a 'fuller life'. Explicit reference is made to the importance of including health care needs. The contribution of brokerage and advocacy is noted

* Recommendation 5: anyone who wants a direct payment should be able to access one by 2003; lists of providers to be made available. There is recognition that some may not want the extra responsibility but that advocacy may have an important supporting role to play. Direct Payments are referred to as self-directed support and individual budgets (see below)

*Recommendation 11: the provision of independent advocacy was to be 'encouraged'.

*Recommendation 25: falls in the chapter on 'working together' that highlights the need for service co-ordination. This is the only place parents with learning disabilities are mentioned explicitly (pt 32) affirming the right to choose to be a parent and the importance of access to parenting skills and support in line with mainstream provision.

The same as you? A review of services for people with learning disabilities

emphasizes the importance of improving the quality of life for people with learning disabilities as well as providing community-based, coordinated services. The needs of people with learning disabilities and the way services are provided is part of the wider policy and legislative framework governing services in Scotland. It sits on a raft of other legislation such as **Modernising Community Care, Social Inclusion: Opening the Door to a Better Scotland and Towards a Healthier Scotland** that aims to improve services and make them accessible for all.

Specifically, **Joint Future** provides the organisational arrangements to ensure that health and social work services work together to deliver the objectives of The same as you? The Joint Partnership arrangements should provide clear leadership and direction for local services.

Recent legislation is also very relevant to people with learning disabilities and includes **The Disability Discrimination Act (1995/2005), The Human Rights Act (1998), Race Relations (Amendment) Act 2000, Adults with Incapacity (Scotland) Act 2000, Community Care and Health (Scotland) Act 2002 and the Mental Health (Care and Treatment) (Scotland) Act 2003.**

Supporting People 2003

The Supporting People programme was introduced in Scotland, in April 2003, when funding was transferred from the Department for Work and Pensions (DWP) to the Scottish Executive as a ring-fenced amount to provide housing support needs for vulnerable groups. The idea was to focus on flexible services moulded around people rather than standardized services. Significant quality of life benefits were recorded for individual people; people with learning disabilities on resettlement programmes were particular beneficiaries. As from December 2008 this pot is no longer ring-fenced but local authorities still have targets to meet.

Adult services – legal framework

The Social Work (Scotland) Act 1968 outlines the general duty on local authorities to promote social welfare through the provision of 'advice, guidance and assistance' and in turn to provide community based and residential services (section 12).

Chronically Sick and Disabled Persons Act 1970 requires local authorities to gather information about the extent of need for welfare services for people with disabilities and to provide information on available services provided both by the authority and other organisations (section 1, 1970 Act - brought into effect in Scotland by the Chronically Sick and Disabled Persons (Scotland) Act 1972).

The **NHS and Community Care Act 1990** sets out the duty on Scottish local authorities to assess needs (by inserting a new section 12A into the Social Work (Scotland) Act 1968). The **Community Care and Health (Scotland) Act 2002** further amended the assessment duty to ensure local authorities take account of any care being provided by an informal carer and consider the views of the carer and the person being cared for before deciding upon an appropriate care package.

The **Community Care and Health (Scotland) Act 2002** extended the rights of informal carers by providing for an independent assessment of a carer's ability to continue caring "carer's assessment" (section 12AA Social Work (Scotland) Act 1968). A carer is someone who offers "a substantial amount of care on a regular basis for another person aged eighteen or over..." (s.12AA(1)). The local authority has a duty to inform carers of their right to this assessment (s 12AB SWSA 1968). **Young carers** (under 16 years) are entitled to a carer's assessment.

A central policy aim is to ensure local authorities and other agencies work in partnership with informal carers (see government guidance CCD 2/2003 - Community Care and Health (Scotland) Act 2002. New Statutory Rights for Carers: Guidance). Paragraph.5.2.2. makes clear that local authorities should 'make information available in formats that are accessible (including tapes, video) and appropriate (especially for young and older carers, carers with learning disabilities and carers from minority ethnic groups)'.

Self-directed support (previously referred to as direct payments) provisions can be found in section 12B,C, Social Work (Scotland) Act 1968 as amended. Guidance lists the groups who may be entitled to self-directed support and these include amongst others: 'Disabled people with parental responsibility to purchase the children's services their children have been assessed as needing; Parents and people with parental responsibility for a child in need (under 16 years) who has been assessed as requiring children's services; Parents and people with parental responsibility for children whose health and development may be impaired or below a reasonable standard without services from the local authority;' (p.4). Section 12 of provides specific guidance for users of children's services and this can be to support them in their parenting role (p.68) (see Circular No. CCD 7/2007 Self-Directed Support – New National Guidance at www.scotland.gov.uk/Resource/Doc/181224/0051499.pdf)

Adult Support and Protection (Scotland) Act 2007

'Adults at risk' are adults, aged 16 and over, who are unable to safeguard their own well-being, property, rights or other interests, AND who are at risk of harm, AND who are rendered more vulnerable to being harmed than other adults by virtue of their disability, mental disorder, illness or physical or mental infirmity.

An officer of the local authority can have rights of access to an individual for the purposes of assessment; intervention orders including banning and removal of individuals, can be sought; also if someone is able to make decisions but deemed to be under 'undue pressure' (for example from a partner or acquaintances) the local authority officer may present an argument for intervention to the sheriff.

As yet there is no established case law and the act may prove to have limited application to parents with learning disabilities and require cautious use.

Children's services – legal and policy framework

A key National Outcome for the Scottish Government is to ensure that all children and young people develop their full potential to become successful learners, confident individuals, effective contributors and responsible citizens in adulthood. These are the clear aims for the Scottish educational system defined in the 'Curriculum for Excellence' programme, which underpins developments in the Scottish educational framework (see at www.ltscotland.org.uk/curriculumforexcellence/index.asp)

Education (Additional Support for Learning) (Scotland) Act 2004

This act replaced earlier special needs provisions for children with serious difficulties and broadened them to encompass those 'with additional support needs' for 'whatever reason' in order to be able to benefit from educational opportunities. The government guidance offers examples that include children where families are disadvantaged, amongst others. Whilst parents with learning disabilities are not specifically mentioned, it is clear that a case might be able to be made for extra educational support for their children.

The additional support should be "directed to the development of the personality, talents and mental and physical abilities of that child or young person to their fullest potential." Eligibility for a coordinated support plan depends on a number of factors, including the severity of needs, as well as the sources of support required. There is also provision for 'supporters' and 'advocates' to help children have their views heard.

Among other things, under the 2004 Act, education authorities must:

- provide independent and free mediation services for all parents of children with additional support needs
- publish information on these services
- provide access to dispute resolution services for all parents of children with additional support needs

The **Getting it right for every child** programme aims to ensure that timely and appropriate support for children is co-ordinated across agencies. All practitioners in adult and children's services are expected to work together to promote the well-being of children through a 'shared approach and accountability that:

- build solutions with and around children, young people and families
- enables children and young people to get the help they need when they need it
- supports positive shift in culture, systems and practice
- Involves working together to make things better' (Scottish Government 2008, p.13)

The policy aim outlined in **Getting it right for every child** is to ensure that children are supported in their growth and development to be:

- Healthy
- Achieving
- Nurtured
- Active
- Respected
- Responsible
- Included
- Safe

(Well-being indicators www.scotland.gov.uk/Topics/People/Young-People/childrenservices/vision)

One of the ten core components of the Getting it right for every child approach is the role of the Lead Professional to coordinate support for children and their families across agencies and to monitor multi-agency activity when required. The Lead Professional role arises when two or more agencies require to co-ordinate their activity to provide the identified assistance to the child and family. (Scottish Government 2008, p.21)

There is an intention to create electronic systems to support the sharing of information between agencies working together for a 'shared purpose'. This includes the development of a Child's virtual shared record (Scottish Government 2008, p.9)

A key component of **Getting it right for every child** is 'A coordinated and unified approach to identifying concerns, assessing needs, agreeing actions and outcomes, based on the Well-being Indicators' (Scottish Government 2008, p.9). A Practice Model has been developed to take account of these elements including an assessment framework (My World Triangle) grounded in an ecological approach to child development; and in more 'complex cases' a Resilience Matrix.

Scottish Government (2008) A guide to Getting it right for every child, at www.scotland.gov.uk/Publications/2008/09/22091734/0

Section 19 of the Children (Scotland) Act 1995 requires local authorities to consult with other statutory and voluntary agencies to prepare and publish plans for the provision of children's services in their area. Government guidance on **Integrated Children's Services Plans** for 2005-2008 required local authorities and National Health Service Boards to jointly produce such plans in consultation with other relevant agencies.

www.scotland.gov.uk/Topics/People/YoungPeople/childrenservices/10262

Getting it right for every child in Kinship and Foster Care (Scottish Government 2007) sets out a child-centred strategy to support kinship and foster care for the benefit of children. One of the key principles is that: 'Unless there are clear reasons why placement within the family would not be in the child's best interests, care within the wider family and community circle will be the first option for the child' (p.3). This would apply to children with parents with a learning disability as to all parents.

This sits alongside the new permanence order set out in the Adoption and Children's Act 2007. This is a flexible order, which should be able to address the changing situation of an individual child. Only the local authority can apply for a permanence order and the application can be made with or without a measure to grant authority for the child to be adopted (section 80, 2007 Act). The local authority will always have the parental right to regulate the child's residence and the responsibility to provide guidance to a child but the birth parents may retain some of their parental responsibilities and rights and other people (e.g. relative carers foster carers can be awarded some).

NHS Quality Improvement Scotland (NHS QIS) **Maternal History Taking Best Practice Statement** August 2008 – Section 6. Early identification/appropriate advice and support for women with learning disabilities accessing maternity services. Specifically there should be accessible information leaflets, parenting classes and the CHANGE book 'You and Your Baby'.

Services to children in need and their families

The Children (Scotland) Act 1995 places duties on local authorities to provide a range of services to 'safeguard and promote the welfare of children in their area who are in need' and to 'promote the upbringing of such children by their families' (section 22(1) Children (Scotland) Act 1995).

A child is 'in need' if they require assistance to ensure they reach a reasonable standard of health and development; or if significant impairment of their health or development is likely without assistance; or the child is disabled; or if the disability of a family member is having an adverse effect on the child (Section 93(4)(a) Children (Scotland) Act 1995).

Local authorities have specific duties to ensure that services for children in need who have disabilities or are 'adversely affected' by the disability of a family member are provided in ways that lessen the impact of the disability and ensure that the child has the opportunity to lead as normal a life as possible. Local authorities are also required to undertake an assessment of a child's needs arising due to disability (section 23 Children (Scotland) Act 1995). Carers of a disabled child have the right to request an independent assessment of their ability to continue caring for the child (section 24 Children (Scotland) Act 1995).

Looked After Children

Section 17 of the Children (Scotland) Act 1995 imposes a duty on local authorities towards children who are "looked after" to ensure that they safeguard and promote the child's welfare, promote contact with those who have parental responsibilities, whilst taking into account the views of the child. A further duty is the provision of advice and assistance with a view to preparing a child for when the child is no longer looked after – often referred to as "throughcare".

Protecting children

Local authorities have responsibilities to make inquiries if a child is potentially in need of compulsory measures of supervision and if so, to refer the child to the Principal Reporter (section 53 (1) Children (Scotland) Act 1995). This provision underpins local authorities' duties to investigate and provide information to the reporter where there are concerns about the care of a child. The police are also required to provide information to the reporter where they have concerns about a child's welfare (section 53(2) Children (Scotland) Act 1995).

Following the Child Protection Audit and Review Report (Scottish Executive 2002) the then government initiated a Child Protection Reform Programme with various policy and practice strands. The Framework for Standards for child protection (Scottish Executive 2004), draws upon the Children's Charter developed by Save the Children in consultation with children and young people with experience of care and protection needs. The framework provides a clear set of standards for all agencies to ensure they have effective measures in place to safeguard children's welfare; and provide an outline of what children and parents should expect from agencies holding responsibility to protect children. Standard 3(2) refers to the importance of supporting parents to be involved in decision making (unless unsafe for the child or other children); and of ensuring parents who have communication difficulties understand the process. There are references to skills and experience in communicating with children (standard 6(1)) but there is no specific guidance regarding parents who have a learning disability.

The main inter-agency guidance for organisations working with children and families where child protection concerns may arise is found in *Protecting Children: A Shared Responsibility Guidance on Inter-Agency Co-operation*. Edinburgh: Scottish Office. This is currently under review by a national working group.

Co-operation in child protection, drawing on the specific expertise of all relevant public agencies including health and criminal justice, is underpinned by joint procedures prepared by inter-agency Child Protection Committees. These procedures cover the arrangements for responding to and sharing of information about allegations of child abuse, and accessing specialist advice or expertise. All agencies including those voluntary and statutory services with responsibilities for disabled parents and disabled children should have arrangements in place for selecting suitable staff, and for supervising, training and supporting them to carry out their tasks.

The guidance emphasises the importance of statutory agencies involving parents when undertaking child protection inquiries indicating the requirements 'to encourage and help parents or carers to express their views and participate in inquiries as appropriate, and keep them informed of progress and decisions'. The only exception would be if any of these activities would compromise the child's safety and a record must be kept of the reason for any decision to limit the level of information or participation by parents (paragraph 1.14).

There is recognition that adults with disabilities may need additional assistance or services to support their parenting role and that potential fears about family 'break-up' may affect decisions to seek help from statutory agencies. There is specific reference to the needs of parents with a learning disability for 'access to independent advocacy to help them participate in child protection interviews, conferences and planning' (paragraph 1.15).

Parents and children (where appropriate) should be advised in writing of the outcome of child protection inquiries. Where there is no substantiation of the concerns triggering the inquiries 'Further support or other services should be offered where necessary' (paragraph 4.23). This is made explicit in paragraph 4.25 'Following inquiries, the local authority may find that a referral does not require further investigation under local child protection procedures, but the child or family needs help in other ways. The local authority should arrange any necessary help or services from child health and social work services, or additional support from education professionals or voluntary agency support services, either directly, or by putting the family in touch with other agencies'.

Parents and carers should be encouraged to attend multi-agency case conferences, as should children, if appropriate. The time and venue of the conference should be arranged giving consideration to the needs of parents and children as well as other professionals (paragraph 4.35).

Partnership between parents and professionals is encouraged and social work services have a responsibility to provide information about child protection processes, the specific concerns identified, the differing agencies' roles and legal powers prior to a case conference. It is recognized that parents may require the assistance of a supporter when they attend a case conference (para 4.44). Guidance also recognizes the importance of providing written information to parents (para 4.47) and of complaints processes (para 4.48).

The professional undertaking a comprehensive assessment of the child and family's circumstances should ensure that consideration is given to whether parents, carers or the child have special needs due to disability or communication difficulties and how these will be addressed (para 4.50).

Criminal justice social workers undertaking social enquiry reports have responsibilities to identify and discuss any child welfare concerns that may come to their attention with children and families social workers in a timely manner (Justice Department Circular 18/2006, Social Enquiry Reports (SER) – Drug Misusing Offenders – Child Protection Issues: Guidance for Social Enquiry Report Authors).

Guidance on child protection and communication with children who are disabled is contained in Scotland's Children: Children (Scotland) Act 1995, Volume 1 - Support and Protection for Children and their Families.

Legal framework for the protection of children

Local authorities have a range of legal measures available to ensure the safety of a child where there is the presence or likelihood of significant harm.

A local authority can apply to a sheriff for a Child Assessment Order in order investigate the circumstances of the child where there are suspicions that a child is being maltreated or neglected and satisfactory assessment is unlikely without the formal order (section 55 Children (Scotland) Act 1995).

Child Protection Orders allow for the urgent removal (or retention) of a child to a place of safety (sections 57-60 of the 1995 Act). Application is to the sheriff by 'any person', which includes local authorities (section 57(1)), or specifically by a local authority (section 57(2)). The criteria are different in each of these sections to take account of distinct circumstances where action is necessary to protect a child. The Sheriff can make directions in the CPO regulating contact between the child and parents (or others), and to the exercise of parental responsibilities including medical examination and treatment (section 58). There are complex provisions regulating the process (which transfers to the children's hearings system) and provisions to recall orders following implementation.

Where it is impracticable to make an application to a sheriff for a child protection order emergency authorisation can be sought from a Justice of the Peace (section 61) to protect a child on the same terms. Authorisation under this section only lasts for 24 hours (section 61(4)). A police constable retains the power to remove a child to a place of safety, but again, only for a maximum of 24 hours (s.61(5),(6)).

There is also provision to exclude a suspected abuser from the household instead of the child (sections 76 -80 Children (Scotland) Act 1995). This may best meet the child's needs for protection and reduce the disruption to the child's life. There must be an adult carer remaining in the household to look after the child and any other children.

Compulsory measures of supervision – the children's hearings system

The children's hearings system deals with children (primarily under 16 years) in need of compulsory measures of supervision. Anyone can refer a child to the reporter who receives all referrals and investigates the circumstances seeking reports from the local authority as required. The grounds of referral are set out in section 52(2) of the 1995 Act and include both offence and care and protection concerns. Following investigation the reporter may decide to take no further action; refer the child and his/her family to the local authority to voluntary support; or arrange a children's hearing if compulsory measure of supervision appear necessary (section 56(6) and section 65(1) 1995 Act).

A children's hearing involves three lay members of the children's panel, any relevant persons ('relevant persons' are defined in section 93(2)(b) 1995 Act and include parents and others, provided they hold parental responsibilities or who care for a child such as a co-habitee), the child in the majority of cases, the social worker and the reporter. The reporter's role at the hearing is to ensure that the process is fair and procedurally correct, and to clarify legal issues if necessary. Local authorities provide social background reports to the children's hearing and at the investigation stage if required. A hearing and sheriffs dealing with a hearings case must consider whether a safeguarder should be appointed. Safeguarders provide an independent report to the hearing and/or sheriff regarding the best interests of the child.

Before the hearing can proceed to discuss the needs of the child the 'relevant persons' and the child must either accept or reject the grounds of referral. If the grounds are not accepted the hearing can either decide to discharge the case or ask the reporter to arrange a formal hearing before a sheriff to seek to prove the grounds (section 65(7) 1995 Act). If a child does not understand the explanation of the grounds the hearing can make the same decision. A formal court hearing is held before the sheriff and if the grounds of referral are proved than the children's hearing is reconvened to make a decision in relation to the child. Relevant persons and/or the child may bring a representative (this can be a friend or relative for example) to the hearing to support them in discussing the case in the hearing (Rule 11 Children's Hearings (Scotland) Rules 1996, SI 1996/3261, the latter set out the detailed regulatory procedures.

In 'complex' cases or where there is a likelihood that an authorisation may be made for the child to be detained in secure accommodation, the hearing may appoint a legal representative for the child. Since June 2009 a hearing (or a business meeting held in advance of a hearing) may appoint a legal representative for a relevant person when certain types of supervision requirement are being considered (i.e. where a child may be required to reside other than with the relevant person; where a relevant person's contact with the child is to be regulated; where parental rights may be affected) and it would enable the person to participate more effectively. This change may be of assistance to parents with a learning disability. The Children's Hearings (Legal Representation) (Scotland) Rules 2002, S.I. 2002/63 as amended contains the detailed rules in relation to children and relevant persons). Legal aid is available where the case has been referred to court for testing of grounds of referral or appeals.

The hearing may decide after discussion with the child, the family and the professionals to make the child subject to a supervision requirement (section 70 1995 Act). Conditions can be attached to the requirement, for example, that the child should live in a specific place, in foster or residential care. The majority of children on supervision live at home. Supervision requirements must be reviewed annually unless requested earlier by the child and/or relevant person(s) or the local authority (s.73). It is also possible for the hearing to set an earlier review date (s.70(7)).

The decision of a hearing can be appealed to the sheriff on the basis that the hearing's decision 'is not justified in all the circumstances of the case' (section 51). On appeal the sheriff has a number of options and can, amongst others, confirm the hearing's decision (s.51(4)) or allow the appeal and discharge the case, or refer back to the hearing for further consideration. There is further appeal to the Sheriff Principal on 'a point of law or in respect of any irregularity in the conduct of the case' (s.51(11)) and, with leave from the Sheriff Principal to the Court of Session. There is also a direct appeal to the Court of Session on the same basis (section 51).

Human Rights Act 1998

The 1998 Act incorporates the European Convention on Human Rights and Fundamental Freedoms into domestic law in the UK. Public authorities, which include social work, education and health services must act in accordance with the fundamental rights set out in the convention. Article 8 provides the 'Right to respect for private and family life'. This ensures that any intervention by the state should be proportionate and lawful. Article 6 'Right to a fair trial' refers to fairness and 'due process' emphasising the need for decision making procedures to be fair and transparent to parents. Article 14 'Prohibition of Discrimination' ensures that the convention rights are available to all without any discrimination.

Disability Equality Duty 2006

The Disability Equality Duty provides a positive duty for public authorities (45,000 in the UK) to introduce policies that actively promote opportunities and prevent discrimination from taking place.

Basically they must pay 'due regard' to the promotion of equality of opportunity between disabled people and other people; the elimination of discrimination that is unlawful under the Disability Discrimination Act and of harassment of disabled people that is related to their disability; the encouragement of participation by disabled people in public life and to take steps to meet disabled people's needs, even if this requires more favourable treatment

For more information visit: **www.dotheduty.org**

The Disability Rights Commission closed at the end of September 2007, and was replaced in October 2007 by the Equality and Human Rights Commission. You can find more information on the duty and the work of the new Commission at: www.equalityhumanrights.com

Organisations have volunteered their own resources for this list, so there is no guarantee that they are examples of best practice. However, we hope they will be helpful.

1. Making information accessible

The Scottish Accessible Information Forum (SAIF) have produced standards for providing information for disabled people. They have also produced a good practice checklist.

They offer training in producing accessible information for frontline staff and for managers. They also offer training on e-communications.

For more information please contact SAIF:

Phone: 0141 226 5261

Fax: 0141 221 9695

E-mail: info@saifscotland.org.uk

The Scottish Consortium for Learning Disability (SCLD) can help organisations to produce information in an accessible way, using words and pictures. They do this in three ways:

- Training for staff on how to make information accessible
- Producing information in easy read format
- Turning all sorts of written information into an easy read format

For more information, contact:

SCLD, Adelphi Centre Room 16, 12 Commercial Road,
Glasgow G5 0PQ

Tel: 0141 418 5420

E-mail: Cath.m@sclد.co.uk

Web: www.sclد.org.uk

ENABLE Scotland

ENABLE Scotland's Accessible Information Unit can convert existing documents to an easy-read format or write new accessible documents. Easy read is a method of writing short sentences in plain English, supported by appropriate graphics.

Bespoke training is available for up to 12 members of staff, where we will work on making your organisation's publications more accessible.

For more information contact:

ENABLE Scotland, 2nd Floor, 146 Argyle St, Glasgow G2 8BL

Tel No: 0141 225 1608

E-mail: easyread@enable.org.uk

Web: <http://www.enable.org.uk>

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, Unit 4, Shine, Harehills Road, Leeds LS8 5HS

Tel No: 0113 3880011

Fax No: 0113 3880012

E-mail: info@changepeople.co.uk

Web: www.changepeople.co.uk

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.

2. Joint protocols and care pathways: good practice examples

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

www.scie.org.uk

NHS greater Glasgow and Clyde and Equalities in Health (2008) Inequalities sensitive practice initiative maternal pathways. Women with learning disabilities.

This care pathway outlines the care standards for midwives supporting women with learning disabilities.

http://www.equalitiesinhealth.org/documents/WomenwithLearningDisabilities_000.pdf

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/>

4. Assessment tools and screening 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. Includes a screening tool.

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

Planning with People is a network of organisations who do person-centred planning, for people and organisations in Edinburgh and surrounding area. Contacts are:

Mags Bryan (Health and Social Care) 0131525 8040
margaret.bryan@edinburgh.gov.uk

Rosie Barclay (Careers Scotland) 0131 313 6072
rosie.barclay@careers-scotland.org.uk

Steve Coulson (Edinburgh Development Group) 0131 476 0522
steve@edg-sco.org

Quarriers run a Person Centred Planning Service.

Contact details:

Louise Goad
Quarriers Person Centred Planning Service
Unit 16 – 18 Ladyloan Place
Glasgow G15 8LB

Tel: 0141 944 7781

E-mail: personcentredplanning@quarriers.org.uk

There is also a West of Scotland Person Centred Planning Network. Contact through Quarriers, as above.

6. Parenting Skills Resources

CHANGE publications:

Planning a Baby booklet

My pregnancy, my choice A book that takes the reader through every stage of pregnancy

You and Your Baby 0-1: a practical handbook for parents with learning disabilities

You and Your Little Child 1-5: a practical handbook for parents with learning disabilities who have toddlers and young children

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 healthy and warm

Children need to be safe

Children need love

Both available from:

BILD Publications, BookSource, 32 Finlas Street, Cowlares Estate, Glasgow G22 5DU

08702 402 182

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

Ann Craft Trust:

Supporting Parents with Learning Disabilities A book for anyone working with parents with learning disabilities.

<http://www.anncrafttrust.org/publications.html>

7. Access to Independent Advocacy

The Scottish Independent Advocacy Alliance has a directory of independent advocacy organisations. You can find out what is available in your area by contacting:

Scottish Independent Advocacy Alliance

69a George Street

Edinburgh

EH2 2JG

Tel: 0131 260 5380

Web: <http://www.siaa.org.uk/>

People First (Scotland) supports self-advocacy groups of parents with learning difficulties in the East and West of Scotland and campaigns for better support for parents with learning difficulties. Contact:

People First (Scotland)

77-79 Easter Road,

Edinburgh

EH7 5PW

Tel: 0131 478 7707

E-mail: peoplefirst1@btconnect.com

Web: <http://www.peoplefirstscotland.org>

8. Training

Parents with learning difficulties from People First (Scotland) can provide training on the issues for parents with learning difficulties and what makes good support.

Contact details above.

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