

# Finding the right support?

A review of issues and positive practice in supporting parents with learning difficulties and their children



Beth Tarleton, Linda Ward and Joyce Howarth

## The Baring Foundation

The Baring Foundation was set up in 1969. In 37 years we have given over £90 million in grants and in 2006 will give more than £3 million.

The purpose of the Foundation is to improve the quality of life of people suffering disadvantage and discrimination. We aim to achieve this through making grants to strengthen voluntary sector organisations which serve them directly or indirectly and by the added value we bring to this.

In 2004, the Foundation launched a special initiative to create a better deal for parents with learning difficulties and their children. We will follow up '*Finding the Right Support?*' with funding for further work to pursue the agenda for action contained here. More details can be found on our website: [www.baringfoundation.org.uk](http://www.baringfoundation.org.uk)



**Norah Fry Research Centre**  
University of Bristol

The Norah Fry Research Centre, University of Bristol, carries out applied research on issues affecting the lives of disabled children and adults with learning difficulties and their families.

---

Further copies of the full report and summary of key findings can be downloaded at:

[www.baringfoundation.org.uk](http://www.baringfoundation.org.uk)

[www.bris.ac.uk/Depts/NorahFry/](http://www.bris.ac.uk/Depts/NorahFry/)

An easy to read summary of findings from the project, called '*Being good parents*', is also available at these websites.

# Contents

<b>List of Boxes and Tables</b> .....	iii
<b>Acknowledgements</b> .....	iv
<b>Executive summary</b> .....	v
<b>PART 1: CURRENT ISSUES AND SERVICES FOR PARENTS WITH LEARNING DIFFICULTIES AND THEIR CHILDREN</b>	
<b>Chapter 1: Introduction</b> .....	1
1. Parents with learning difficulties today .....	1
2. The project .....	5
3. The literature .....	6
4. The views of parents with learning difficulties .....	8
5. This report .....	11
<b>Chapter 2: What kinds of services are supporting parents with learning difficulties?</b> .....	13
1. Agencies providing support to parents with learning difficulties .....	13
2. The range of professionals involved in teams providing services for parents with learning difficulties .....	14
3. The priority given to supporting parents .....	14
4. The types of service provided to parents with learning difficulties .....	16
5. Assessing parents' support needs .....	17
6. Assessing the needs of the children .....	17
7. Referral routes .....	17
8. Eligibility criteria .....	17
9. The number of parents with learning difficulties supported by individual services .....	18
10. The number of families supported by individual workers .....	18
11. The specific training received by professionals .....	19
12. The training professionals wanted .....	19
13. Support for staff .....	20
14. Working with other agencies and professionals .....	21
Summary .....	21
<b>Chapter 3: The issues faced by parents with learning difficulties and the workers who support them</b> .....	23
1. Negative stereotypes and assumptions .....	23
2. Lack of awareness of parents with learning difficulties and their support needs .....	24
3. Fixed ideas about parenting and what should happen to children .....	24
4. Lack of consistency and clarity on what constitutes 'good parenting' .....	25
5. Parents' lack of engagement with children and family services .....	25
6. Late or crisis point referrals .....	27
7. Lack of time, resources and service coordination .....	27
8. Concerns about the implications of the Adoption and Children Act 2002 .....	27
Summary .....	28
<b>PART 2: POSITIVE PRACTICE</b>	
<b>Chapter 4: Parenting with support</b> .....	29
1. Parenting with support: core themes .....	29
2. The experiences of parents with learning difficulties .....	33
Summary .....	37

<b>Chapter 5: Identifying parents with learning difficulties and providing appropriate support in pregnancy</b>	.39
1. Identifying parents with learning difficulties	.39
2. Tools for identifying if parents have a learning difficulty	.39
3. Training and support for professionals in identifying parents with learning difficulties	.40
4. Pre-pregnancy advice	.41
5. Antenatal support	.41
Summary	.43
<b>Chapter 6: Providing effective support</b>	.45
1. Assessing parents' support needs	.45
2. Skills training and knowledge development	.47
3. Parenting groups	.48
4. What sort of support do parents want?	.51
5. Flexible support to meet families' changing needs	.55
6. Emotional support	.57
7. The role of the extended family	.58
Summary	.61
<b>Chapter 7: Engaging with other services, advocacy and multi-agency support</b>	.65
1. Helping parents engage with other services	.65
2. The role of advocates	.67
3. Multi-agency working	.70
Summary	.74
<b>Chapter 8: Child protection and the courts</b>	.77
1. Ensuring children's welfare – by providing the right support	.77
2. Child protection and the courts	.79
Summary	.85
<b>PART 3: MOVING FORWARD</b>	
<b>Chapter 9: Conclusions and recommendations</b>	.87
1. Parents with learning difficulties today	.87
2. Parenting with support: what does it mean in practice?	.89
3. Parenting with support: the barriers	.90
4. Parenting with support: from margin to mainstream?	.92
5. Recommendations	.93
(i) What is needed at national (policy) level?	.93
(ii) What needs to be available at a local level?	.94
(iii) What needs to be available for individual parents with learning difficulties and their children?	.95
(iv) What further research or development projects are needed?	.96
<b>References</b>	.97
<b>Appendix 1: Methodology</b>	.103
<b>Appendix 2: What kind of services are supporting parents with learning difficulties?</b>	
<b>Tables and further information on questionnaire respondents</b>	.105
<b>Appendix 3: Care Pathway for Pregnant Women with a Learning Disability in Stockport</b>	.108

# List of Boxes and Tables

## 1. Boxes

Supporting parents with learning difficulties in England . . . . .	2
Supporting parents with learning difficulties in Scotland . . . . .	3
CHANGE . . . . .	3
Key research on families where a parent has a learning difficulty . . . . .	8
Circles Network . . . . .	10
Funding . . . . .	14
Setting up multi-agency groups . . . . .	30
What is keyworking . . . . .	31
What helps people with learning difficulties be good parents? . . . . .	32
‘Valuing Families’ in Leicestershire . . . . .	36
The role of the midwife . . . . .	42
Community based assessment . . . . .	46
The pregnancy album . . . . .	48
Elfrida Society Parenting Group . . . . .	50
Stockport Community Team for parents with learning disabilities . . . . .	53
An occupational therapist’s role . . . . .	54
Parenting support service, North Tyneside . . . . .	56
‘Expected to be a parent’: the perspective of a service supporting Bangladeshi parents . . . . .	59
Kinship care . . . . .	61
Home-Start . . . . .	66
The role of advocate . . . . .	68
Training for advocates working with parents with learning difficulties . . . . .	69
Multi-agency working . . . . .	70
Supporting parents with learning difficulties in South Norfolk . . . . .	71
Special Parenting Service, Cornwall . . . . .	73
Making information easier to understand . . . . .	80
Parents and children: rights and responsibilities in court . . . . .	81
Making courts less frightening . . . . .	82
Advocacy and the courts . . . . .	83
The role of the Guardian . . . . .	84
Disabled Parents Network . . . . .	91

## 2. Tables

Table 1: The range of agencies providing support to parents . . . . .	105
Table 2: The range of professionals involved in teams providing services to parents with learning difficulties . . . . .	106
Table 3: The types of service provided . . . . .	106
Table 4: Types of assessment used to assess parents’ needs . . . . .	107
Table 5: Number of families supported by individual workers . . . . .	107
Table 6: Most frequently cited kinds of training received by workers . . . . .	107

# Acknowledgements

We are grateful to the Baring Foundation for their support for this study, and to David Cutler (Director), Tessa Baring (Chair), Ann Buchanan and Nicholas Deakin (Trustees) of the Foundation and Oliver Russell (adviser) for their helpful comments, advice and support along the way.

The project would not have been possible without the enthusiastic support and comments of many professionals, advocates and others throughout the UK, who were keen to share with us their views and experience of supporting parents with learning difficulties, and their families. In particular, we are grateful to those who publicised the project in their organisation's newsletters or on their websites, and especially to those who completed our web questionnaire, who participated in follow up telephone interviews or who allowed us to spend time with them at their services or meetings.

We owe a particularly large debt to the 13 parents with learning difficulties who acted as consultants to the project as it progressed and to the 17 other parents we met in other parts of the country, who shared with us their often painful, as well as positive, experiences of parenting.

A number of experts in the field helped us at different stages of the project; we are grateful to Sue McGaw, Jenny Morris, Michele Wates and many others for information, references, contacts, updates, suggestions and advice.

We are also grateful to Marcus Witt, for help with the literature review and to Nick Tarleton, for work on the project's website.

Finally, we owe a big thank you to colleagues at the Norah Fry Research Centre, University of Bristol, who commented on early drafts of various sections of this report or helped administratively in different ways, and in particular to Sammantha Cave for her calm and careful commitment to the report's production throughout.

# Executive summary

An increasing number of adults with learning difficulties are becoming parents. In about 50% of cases their children are removed from them, usually as a result of concerns for their well-being and/or an absence of appropriate support. This study set out to map the issues confronting parents and professionals in this area, along with strategies for positive practice in providing parents with learning difficulties and their children with 'the right support' to stay together as a family.

## Key findings

- **A wide variety of agencies and professionals** are engaging with the issues around supporting parents with learning difficulties and their children including community nurses, social workers, health visitors, midwives, psychologists, speech and language therapists, occupational therapists and advocates.
- There are a range of **barriers to the provision of appropriate support** to parents including negative, or stereotypical, attitudes about parents with learning difficulties on the part of staff in some services.
- Many professionals are trying to help parents overcome these barriers so that they can **parent with support**. To achieve this professionals are:
  - **raising awareness of parents with learning difficulties** and their support needs with non learning disability specialist services
  - developing **multi-professional and multi-agency** support for them and their families
  - **empowering parents with learning difficulties**.
- **Effective support** involves a wide range of strategies, including early identification of parents with learning difficulties; support during pregnancy; assessment of support needs; skills training; help at home; parenting groups; flexible support to meet families' individual and changing needs; helping parents to engage with children and family services; and multi-agency working.
- The provision of **easy to understand information** on all aspects of parenting and **advocacy** support are also critical, especially during **child protection and judicial proceedings**.
- Professionals working in services for adults with learning difficulties need **training** in child protection issues; those involved in children's – or generic – services need training about adults with learning difficulties and their support needs.
- Many adults with learning difficulties are deemed 'too able' to qualify for the support services they need. **Eligibility criteria for services** need to take account of their additional needs for support for parenting.
- The development and spread of good practice in this area requires **action at different levels**: the individual parent and family; local services; and at national (policy) level.

## Background

There are no precise figures on the number of parents with learning difficulties in the population. The most recent statistics come from the first national survey of adults with learning difficulties in England, where one in 15 of the adults interviewed had children (Emerson et al, 2005). Whatever the figure, it is generally acknowledged that their number is steadily rising and that they 'represent a sizeable population whose special needs have so far not been adequately addressed by the health and social services' (Booth, 2000). National policy in England commits government to 'supporting parents with learning disabilities in order to help them, wherever possible, to ensure their children gain maximum life chance benefits' (DH, 2001), as does the Scottish equivalent, *The Same as You?* (Scottish Executive, 2000). Nonetheless, parents with learning difficulties are far more likely than other parents to have their children removed from them and permanently placed outside the family home. The English national survey cited above found that 48% of the parents with learning difficulties interviewed were not looking after their own children (Emerson et al, 2005) while worldwide studies put the rates of child removal from parents with learning difficulties in the range of 40% to 60% (McConnell et al, 2002).

## Who is providing support to parents with learning difficulties?

A wide variety of agencies and professionals are engaging with the issues around supporting parents with learning difficulties and their children including: community nurses, social workers, health visitors, midwives, psychologists, speech and language therapists, occupational therapists and advocates. They are providing a diverse range of services including assessments, help in the home, skills training, emotional support (particularly through the child protection and judicial process) and advocacy. Various assessments are in use to ascertain parents' support needs; the most frequently cited was the *Parent Assessment Manual* (McGaw et al, 1998). Children's support needs were generally assessed by staff in children and family services.

## Barriers to support

There are a range of barriers to the provision of appropriate support to parents including negative, or stereotypical, attitudes about parents with learning difficulties on the part of staff in some services. For example, it was felt that some staff in services whose primary focus was *not* learning difficulties (eg in children and families teams) did not fully understand the impact of having learning difficulties on individual parents' lives; had fixed ideas about what should happen to the children of parents with learning difficulties and wanted an outcome that did not involve any risks (which might mean them being placed away from their family); expected parents with learning difficulties to be 'perfect parents' and had extremely high expectations of them. Different professionals often had different concepts of parenting against which parents were assessed. Parents' disengagement with services (because they felt that staff had a negative view of them and 'wanted to take their children away') was also an issue, as were referrals to support services which were too late to be of optimum use to the family – often because workers lacked awareness of parents' learning difficulties or because parents had not previously been known to services.

## Parenting with support

Parents with learning difficulties can often be 'good enough' parents when provided with the ongoing emotional and practical support they need. The concept of 'parenting with support' underpinned the way in which professionals were providing parents with learning difficulties with appropriate help. These professionals were engaging in educating other staff about parents with learning difficulties and their support needs through attendance at relevant forums and multi-agency meetings and by providing training. Professionals in services working with parents with learning difficulties were acting as mediators between the parents and children and family and other services. They were supporting parents to develop parenting skills and to overcome issues in their lives that were negatively impacting on their ability to be 'good enough' parents. At the same time they retained a focus on child protection, reporting any concerns to children and family services. They were trying to facilitate coordinated multi-agency support to families and empower the parents in a variety of ways.

## Strategies for positive practice

Professionals can support adults with learning difficulties to parent successfully by adopting a wide range of strategies in the following areas:

- **Early identification of parents with learning difficulties**

eg. Through screening tools, to help other staff identify if an adult has a learning difficulty, and by developing protocols for joint working and care pathways.

- **Pre-pregnancy and antenatal advice and support**

Through easy to understand information; support and time for parents to understand the choices available; early contact with relevant services; awareness on the part of generic services of the needs of prospective parents with learning difficulties; close working with maternity services.

- **Assessing support needs**

Through multi-professional/agency and competency (rather than IQ) based assessments, taking account of the comprehension level of parents (so that professionals know how best to communicate with them) and allowing sufficient time, so that assessments can be properly explained to the parents.

- **Providing skills training and support for parents**

This requires early assessment of competencies; easy to understand information or adapted material; teaching in a person centred way, with concepts broken down into small parts; close work with midwives, health visitors or other appropriate specialists; time to work at the parent's pace and to liaise with others; praising and acknowledging their skills and supporting them in creative ways, rather than judging them; being honest and clear about expectations of them; explaining different workers' roles and boundaries; helping parents engage with other professionals and agencies; flexible support responsive to the family's needs at different times, including as children grow older; ongoing support, including after children have been adopted.

- **Parenting groups**

Parenting groups have a key role to play in providing parents with informal support. They can use mainstream parenting materials adapted for parents with learning difficulties; focus on issues of importance to parents at the time, eg harassment, bullying, healthy food; provide peer support and recognition of achievements and sharing of experiences; reduce isolation; provide social support during school holidays; enable access to community facilities and ongoing contact with workers for informal advice and support.

- **Involving the extended family**

The extended family can be a valuable source of support to parents and their children, but on the parents' terms so that they can be in control. Professionals need to avoid getting involved in family feuds, and be clear in discussions with extended family members about how the child protection process works.

- **Helping parents to engage with other agencies**

This can be achieved through awareness raising and joint training with mainstream services about parents with learning difficulties and their support needs; recognising wider social issues impacting on the family (eg housing problems); provision of an advocate, especially during child protection processes; supporting parents to prepare for, and attend meetings; building up parents' confidence by practising meeting skills in parents' groups.

- **Multi-agency working**

Multi-agency working is critical if parents are to be supported effectively. It can be facilitated by ongoing meetings and communication; the development of joint protocols, policies and care pathways; key working; and clearly planned, co-ordinated and consistent services.

- **Advocacy for parents with learning difficulties**

Advocates can play a vital role in supporting parents with learning difficulties, particularly when they are involved in child protection or judicial processes. To do this effectively, advocates (both paid and unpaid) need understanding of all the systems involved, both adult and child protection. There is a significant need for more independent advocates able to negotiate with all parties - and challenge services when necessary. In the meantime, the advocacy role is often taken on by workers who are not formally advocates, in an attempt to ensure that parents' voices are heard.

- **Child protection awareness**

All professionals need an understanding of child protection if they are to engage appropriately with other services. Those with limited expertise in this area need specific training, supervision and support. The provision of ongoing support from services can prevent difficulties encountered by parents from developing into child protection issues.

- **Child protection and the courts**

Parents need an advocate or support during their case, and clear explanations and easy to understand information about the process and the roles of the different professionals involved. They need extra time with solicitors, so that everything can be carefully explained to them and support to visit the court beforehand. Workers involved with

parents with learning difficulties need training in report writing and court appearances. Solicitors need to ensure that appropriate reports are put before the court, and that the process is slowed down to give parents a better chance to understand and participate. While judges cannot make local authorities provide appropriate services, in some areas they are becoming more aware of the need for positive support for parents and for competency based (rather than IQ based) assessments.

- **Training for staff**

Only half of the workers supporting parents with learning difficulties, who responded to the study's questionnaire, had undertaken specific training for the role, such as training on child protection and understanding the support needs of parents with learning difficulties. The training wanted by professionals included sessions on child protection, training by parents with learning difficulties about their needs, good practice in assessing support needs and strategies to support parenting. Joint training with other services and professionals was seen as a route to mutual understanding and more harmonious working.

## Recommendations

### (i) What is needed at national (policy) level?

1. **Practice guidance:** joint DfES/DH practice guidance for children's and adult services on working together to support parents with learning difficulties and their children.
2. **National training programme:** funding for a national training programme on supporting parents with learning difficulties and their children for professionals in both learning disability and children's services.
3. **Standards, targets and performance indicators:** CSCI (Commission for Social Care Inspection) standards to include the criterion that if parents with learning difficulties have their children removed from them, this is *not* because of lack of support from adult services. (Such a standard was included in the previous national inspection of learning disability services: standard 2, criterion 2.8; SSI, 2001). Appropriate performance indicators to be introduced.
4. **Advocacy:** increased, ongoing, funding for advocacy services to support parents with learning difficulties, especially when involved in child protection and judicial processes.
5. **Guidelines:** on the involvement of parents with learning difficulties in child protection and judicial processes.
6. **Support to develop a national network:** sharing good practice around supporting parents with learning difficulties.
7. **Demonstration and dissemination:** more demonstration/pilot projects on supporting parents with learning difficulties to be funded and evaluated, with good practice disseminated.
8. **Accessible information:** such as *You and Your Baby*, the accessible book produced by CHANGE (Affleck & Baker, 2004), to be made more widely available to parents with learning difficulties and the services supporting them.

9. **Resources for professionals:** the Barnardo's publication *What Works for Parents with Learning Disabilities?* (McGaw & Newman, 2005) to be widely distributed to all children's services and adult learning disability teams.
10. **Government departments:** issues relating to young people with learning difficulties to be included in work by the Social Exclusion Unit and the DfES on teenage pregnancies. Officials from all the relevant government departments (eg. DfES Safeguarding Unit, DfES Family Division, Valuing People Support Team, DH Disability Policy branch, DH Women's Health and Maternity Team, The Office for Disability Issues) to meet and work together to improve services to parents with learning difficulties and their children.
11. **Direct payments:** dissemination of advice (and possibly targets) around the use of direct payments to support adults with learning difficulties to help them parent.

**(ii) What needs to be available at a local level?**

1. **Multi-professional and multi-agency working:** supported by joint training and strategy development; care pathways and protocols for joint working, including clarity over different professionals' roles and boundaries.
2. **Local, multi-professional, multi-agency forums:** for discussion and support.
3. **Keyworking:** to support parents with learning difficulties and their families.
4. **Training:** for staff in generic and family support services – on identifying and supporting parents with learning difficulties; and for staff working in specialist adult learning difficulty services – about child protection.
5. **Competency-based assessments:** (eg McGaw et al, 1998) and training in undertaking them.
6. **Skills training and other interventions:** access to a range of interventions, and expertise/training in delivering them in the parents' home.
7. **A range of support services:** which can be provided, and funded, long term.
8. **Group support:** through parents' groups, which also help to increase parents' social networks.
9. **Partnership working with parents:** both in relation to bringing up their own children and also in the delivery of training or planning for the development or delivery of support services.
10. **Close working with mainstream services:** identification and creation of effective systematic links between generic services, such as maternity services, doctors, schools, mainstream parenting projects and specialist learning difficulties teams, so that services do not have to wait for problems to arise, before parents can be assessed on their needs for support.
11. **Joint working:** local learning disability trusts/social services departments and children's trusts to jointly fund posts to coordinate support to parents with learning difficulties and their families. This could be one person acting as a link between agencies or a specialist adult learning difficulty post within children's services and a specialist children's post within adult learning difficulty services.

**12. Appropriate eligibility criteria for assessments for services:** many parents with learning difficulties do not currently reach the thresholds for community care services or support. They only show up on services' 'radar' if their children are seen as Children In Need or as being at risk. Local authorities need to be responsive to the fact that adults with learning difficulties may need an assessment, specifically triggered by their needs as parents. This is consistent with the *Fair Access to Care Services'* (DH, 2002) requirement that social roles (including parenting) should be included in the assessment. Procedures need to be in place so that children do not have to be perceived as clients of social services in order for their parents' support needs as parents to be met by local agencies.

**(iii) What needs to be available for individual parents with learning difficulties and their children?**

**1. Easy to understand information:**

- (i) about all aspects of parenting (The CHANGE book, *You and Your Baby*, 2004, is a helpful accessible resource).
- (ii) on the support available – whether from mainstream services, like maternity services, or a specialist learning disability team.
- iii about child protection and judicial processes.

**2. Advice:** parents frequently need advice in multiple areas of their lives, not just around the forthcoming baby. This includes advice on benefits and how to handle problems in relation to poor housing, harassment and so on.

**3. Skills teaching:** and other focussed help as necessary.

**4. Ongoing support:** adapted to changing circumstances as the child gets older and continuing if (and after) a child is adopted.

**5. Consistency and clarity:** from the professionals involved about their expectations of them as parents.

**6. Keyworking:** so that parents are not confused by different interventions by different professionals.

**7. Advocacy:** whether professional or voluntary, to support parents, particularly if they are involved in child protection or judicial processes.

**8. Informal support:** eg via a Circle of Support or Home-Start.

**9. Encouragement and affirmation:** so that parents can gain the confidence to engage positively with services and demonstrate that they can be good enough parents with support.

**10. Contact with other parents:** for example through parents' groups, so that they can share skills and experiences.

**11. Parent involvement:** in the development of new services, training of professionals and other initiatives.

**(iv) What further research or development projects are needed?**

**1. Fathers with learning difficulties:** most of the research, literature and support and intervention services focus on mothers with learning difficulties, with the

exception of small scale but illuminating studies from Iceland (Sigurjonsdottir, 2004) and Tower Hamlets in London (O'Hara & Martin, 2003) and a fathers group in South Norfolk. Our research, and the recent national survey, confirm that fathers with learning difficulties are heavily involved in parenting their children (Emerson et al, 2005). Research and further work in this area would be timely.

2. **Older children/teenagers:** much of the existing research focuses on families with young children. What are the issues and challenges as children get older?
3. **Issues for parents with learning difficulties from different minority ethnic groups:** including issues of consent. (There has been very little in this area to date, with the exception of the small scale study reported by O'Hara & Martin, 2003).
4. **Direct payments:** how can they be used to support parents with learning difficulties?
5. **Courts:** how can they be made more accessible? What strategies can help members of the judiciary and parents with learning difficulties involved in court proceedings?
6. **Advocacy:** what makes for effective advocacy for parents with learning difficulties and how can this be provided?
7. **Support after adoption:** what is, or would, constitute good practice in this area?
8. **Parenting with support:** what services are needed to facilitate this and how are they best provided?
9. **Cost/benefit analyses:** what are the respective costs – and or benefits – of placing and maintaining a child in care, as compared with the costs of providing effective support to the family so that the child can remain safely at home?

# Chapter 1 Introduction

## *I've learned how to be a mum*

(Mother with learning difficulties, *Woman's Hour*, August 24 2005)

### 1. Parents with learning difficulties today

The number of parents with learning disabilities<sup>1</sup> who are forming relationships and having children has steadily increased over the last 20 years (DH, 2001). No one knows their precise numbers, since definitions of 'learning disability' vary and adults with 'mild' learning difficulties may only come to the attention of statutory services if they have problems parenting their children but go unnoticed otherwise. Those studies that have been done in this area have used different population bases and parameters (Booth et al, 2005a), so that estimates vary wildly. For example, McGaw (1997) suggested that there might be 250,000 parents with learning difficulties known to health and social services agencies in the UK, while other estimates have been lower (Booth & Booth, 2004). The most recent figures come from the first national survey of adults with learning difficulties in England which found that one in 15 of the 2,898 adults interviewed had children (Emerson et al, 2005).

Whatever the true figure, it is generally acknowledged that the number of parents with learning difficulties is steadily rising and that they now 'represent a sizeable population whose special needs have so far not been adequately addressed by the health and social services' (Booth, 2000).

It is also clear that parents with learning difficulties are far more likely than other parents to have their children removed from them and permanently placed outside the family home. Worldwide, studies of parents with learning difficulties report rates of child removal in the range of 40–60% (McConnell et al, 2002). The English national survey of adults with learning difficulties cited above found that 48% of the parents with learning difficulties interviewed were not looking after their own children (Emerson et al, 2005). Other work in the UK indicates one sixth of children subject to care proceedings have at least one parent with learning difficulties, with this figure rising to almost a quarter if parents with borderline learning difficulties are included, with children being permanently placed away from home in 75% of these cases (Booth et al, 2005a).

The conventional assumption has been that the intellectual limitations of the parent will, almost inevitably, lead to adverse outcomes for the child. There is now good evidence that abuse is rare amongst parents with learning difficulties (Llewellyn et al, 2003) but the available evidence suggests that child protection authorities and courts frequently presume that parenting failure or child neglect are inevitable and irremediable (McConnell et al, 2002).

Traditionally, there has been a huge tension for service providers, particularly social workers, in relation to parents with learning difficulties. Child and family social workers, charged with protecting children's welfare, have been concerned that children living with parents with learning difficulties will almost inevitably be at risk. Hence, the strong likelihood for parents that their children will be placed away from the family home. Professionals in services supporting adults with learning difficulties tend, by contrast, to

<sup>1</sup> The terms 'learning difficulty' and 'learning disability' are used interchangeably in this report.

be concerned to ensure that these adults receive appropriate and adequate support to parent successfully – thus reducing the likelihood of their children being removed.

This tension – between protecting children and upholding the rights of parents – is real and considerable (DH, 2001; McGaw & Newman, 2005). But the research literature, developing practice, and the findings of this project suggest that the polarisation between upholding the rights of the parents and those of the child may be artificial. Parents with learning difficulties also want to protect the welfare of their children and are more likely to be able to do so if they are assisted and supported at critical stages (McGaw & Newman, 2005). That support is more likely to yield improved outcomes for both parents and children if the professionals delivering it have had access to appropriate training: on child protection (for community nurses, social workers and others working in adult services) and on working with adults with learning difficulties (for health visitors, midwives and those involved in child protection and children and family services).

Encouragingly, government policies (see Box), grass roots practice and even societal attitudes are showing signs of change. At a policy level *Valuing People* committed the English government to ‘supporting parents with learning disabilities in order to help them, wherever possible, to ensure their children gain maximum life chance benefits’ (DH, 2001). In a similar vein, *The Same as You?*, the review of services for people with learning disabilities in Scotland, required that ‘local authorities and NHS Trusts should make sure that the needs of parents with learning disabilities and their children are identified and met’ (Scottish Executive, 2000). *The National Service Framework for Children, Young People and Maternity Services for England* (DfES/DH, 2004) states specifically that local maternity services should address the needs of women with learning disabilities and physical impairments, and take into account their communication, equipment and other support needs.

## **Supporting Parents with Learning Difficulties in England**

***People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child's needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support.***  
(DH, 2001, para 7.40)

***At a local level, it will be the responsibility of the Director of Social Services ...to ensure effective partnership working for parents with learning disabilities between children's and adult teams. Partnership Boards should ensure that services are available to support parents with a learning disability.***  
(DH, 2001, para 7.43)

## Supporting Parents with Learning Difficulties in Scotland

***Some people with learning disabilities may choose to be parents. As with other parents, they will need a range of support and other help from their families and other agencies. Like other people, parents with learning disabilities can benefit from training and support in developing parenting skills.***

(Scottish Executive, 2000, para 6.32)

More generally, the Human Rights Act 1998 stipulates that children and their parents have the right to enjoy a family life together. The desired outcomes of adult services, put forward by the Green Paper on adult social care, include the exercise of choice and control, and freedom from discrimination (DH, 2005). The Disability Discrimination Act 2005 sets out a new 'disability equality duty' on all services, including the public sector, which means public services must promote and provide 'equality of opportunity' to disabled people, including disabled parents. Finally, the Prime Minister and his Strategy Unit make a commitment in their report to 'improving the life chances of disabled people so that [they]...have full opportunities and choices to improve their quality of life and be respected and included as equal members of society' (Prime Minister's Strategy Unit, 2005). All these signal a positive shift in attitude at policy level, which is likely to lead in the future to a better outcome for disabled people in general, and parents with learning difficulties more specifically.

At a grass roots level, the last few years have seen a mushrooming of parenting support and advocacy services, which have grown up in an attempt to provide parents with learning difficulties with the help they need to keep their children and bring them up in a way which maximises their life chances.

Locally and nationally, some parents with learning difficulties have also become active in campaigning for better treatment and support for themselves and their children, most notably with the organisation CHANGE, a national organisation run by disabled people, working for equal rights for all people with learning difficulties. CHANGE has been at the forefront of activity to achieve better support for parents with learning difficulties through its campaign *Fighting for our Children*, a series of accessible publications on being a parent, and the involvement of parents with learning difficulties in training professionals who support parents or are concerned with children's welfare (see Box).

## CHANGE

### Fighting for our Children

On the 11 January 2005, over 250 parents with learning disabilities and people who work with them, attended a National Gathering organised by CHANGE.

***The gathering heard from parents who had brought up their children, sometimes with and without support from services. We heard about things that organisations of people with learning disabilities are doing to help parents with learning disabilities look after their children. And we heard about services that are working with parents with learning disabilities and giving them the support they need... The Gathering also***

continued overleaf

***heard from parents who had lost their children into care. These parents felt they had not been given a chance.***

(CHANGE, 2005, pp 2-3)

After the national gathering parents with learning difficulties took the key demands to a meeting with government officials in the relevant different branches of the Department of Health dealing with child protection, maternity and women's health services, families, and people with learning difficulties, as well as the Department for Constitutional Affairs. One of their demands was for Practice Guidance, to help professionals working with parents with learning difficulties at a local level. This has now been agreed.

### **Accessible information**

CHANGE has produced a range of illustrated accessible publications on parenting, including *Planning a Baby* and *You and Your Baby* (Affleck & Baker, 2004), as well as a CD Rom of pictures from the *You and Your Baby* book. Parents with learning difficulties nationally are now contributing to another publication, *You and Your Little Child*, 1-5. For example, a parents' group in Newcastle is writing recipes on cooking for your small child on a budget. CHANGE have recently received funding to produce a further accessible book: *My Pregnancy, My Choice*, covering pregnancy and birth.

### **Training**

A training pack has been produced by parents with learning difficulties in CHANGE which can be used to train professionals around subjects including: communication, support, working together, child protection and families' lives. Parents from CHANGE are training six parents' groups nationally on how to deliver this training. The parents will then link to local training networks and universities in order to deliver the training to social workers (including child protection professionals), health visitors, midwives and GPs.

For more information:

**CHANGE**

**Unity Business Centre, Units 19 & 20**

**26 Roundhay Road, Leeds, LS7 1AB**

**Tel: 0113 243 0202**

**Email: [changepeople@btconnect.com](mailto:changepeople@btconnect.com)**

At the same time there has been a shift of public attitudes in some places, most notably seen in the *Daily Mail's* recent championing of the case of a family in Essex, where two children, whose mother has a mild learning difficulty, were removed from the care of their parents, to be placed for adoption (*Daily Mail*, August 2005). Whatever the merits or motivation of the *Mail's* intervention, the case prompted a flurry of media coverage in the newspapers, and on radio and television, exploring the 'moral dilemmas' (*Woman's Hour*, August 24 2005) it highlighted. Was it fair for adults with learning difficulties to be allowed to exercise their choice to have children, only to routinely suffer the enormous distress of having those children removed from them? Could things be handled better and differently?

What can – or indeed is – being done, to support parents with learning difficulties, and their children, to maximise their chances of staying together as a family and living regular, happy lives? This report tries to offer an answer to that question, based on the findings of a mapping study commissioned by the Baring Foundation with a view to promoting more widespread positive practice in this contested area.

## 2. The project

The Baring Foundation is a generalist grant maker, with much of its work aimed at tackling discrimination and disadvantage. In 2004 they established their initiative ‘A Better Deal for Parents with Learning Difficulties and their Children’. The first step in this process was to fund this review of what was known about parents with learning difficulties and their children, and the kinds of services that already existed to support them in the UK. The study was to examine the support services available for parents with learning difficulties and their children, with a particular view to identifying examples of good practice, along with a review of research, policy and practice in this field.

This preliminary – and relatively short – study will inform a subsequent phase of the programme, which Baring will fund to promote, extend and sustain more positive practice in this area.

Material for this project was collected through the following means:

- **A review of the relevant literature and resources** (see Section 3 below)
- **Meetings with an advisory group of parents with learning difficulties** – established in the Bristol area to inform the project and its development at every stage (see Section 4 below)
- **Consultation with experts in the field**
- **A paper and web-based questionnaire**, promoted through relevant professional and organisational networks in all four countries of the UK, including services known to be supporting parents with learning difficulties
- **21 telephone interviews**, to gather fuller information about positive practice from some of those who completed questionnaires
- **Case study visits** to six services in different parts of the UK, including interviews and meetings with parents with learning difficulties (17 in total), practitioners, advocates and service managers
- **Contact with experts, other visits and conferences** throughout the lifetime of the project to gain additional information
- **Interviews with professionals and others involved with parents with learning difficulties and their children in the court system.**

More details on the project’s methodology can be found in Appendix 1.

### 3. The literature

There is now a substantial body of literature on the issues affecting disabled parents generally. Particularly useful overviews include: Goodinge, 2000; Morris, 2003; Olsen & Clarke, 2003; Newman & Wates, 2004; Olsen & Tyers, 2004; Olsen & Wates, 2003; SCARE, 2005b; Wates, 2002; SCIE, 2006.

Parents with learning difficulties will encounter many of the same problems as other disabled parents. But they are likely to encounter additional barriers too, as a result of their learning difficulty. These may range from prejudicial assumptions on the part of others about their ability to parent, to difficulties in understanding written or complex information, or managing bills and money.

The most helpful reviews of literature, and research evidence, on issues affecting parents with learning difficulties are to be found in three key sources:

- A SCARE (Social Care Access to Research Evidence) briefing on *Helping parents with learning disabilities in their role in parents* (SCARE, 2005a)
- A chapter by Gwynnyth Llewellyn and David McConnell (from Sydney, Australia) 'You have to prove yourself all the time: people with learning disabilities parenting' (Llewellyn & McConnell, 2005)
- Sue McGaw and Tony Newman's *What works for parents with learning disabilities?* (2005)

Key messages extracted from these reviews include the following:

- The majority of children born to parents with learning difficulties do not have learning difficulties themselves.
- Low socio-economic status, unemployment and social isolation or exclusion are all known to have an adverse effect in general on parents and their parenting skills; parents with learning difficulties are at greater risk than other parents of experiencing these disadvantages.
- Most of our evidence comes from parents known to social care or disability agencies; we simply do not know much about parents with learning difficulties who have not been identified or referred to the service system.
- Most of what we know relates to *mothers* with learning difficulties. We know almost nothing about fathers with learning difficulties.
- Studies have shown that parents with learning difficulties can and do learn child care, home safety, child health and how to interact with their children. There has been a steady increase in the range of parent education programmes available. Home based programmes are more successful than others.
- A range of interventions are needed, from which service providers can 'pick and mix' to suit the needs of individual families.
- There is substantial variation in outcomes among children of parents with learning difficulties, but most of them reach the same levels of attainment as their peers. The presence of at least one consistent and supportive adult in children's lives appears to be very influential.

- Parents with learning difficulties are 15 to 50 times more likely than other parents in the community to have their children removed from them and placed in care.
- Allegations of abuse by parents with learning difficulties are rare; children are more likely to be removed on the grounds that they are at risk of harm due to neglect, including lack of stimulation.
- Lack of support services are a key factor in influencing court decisions.
- The most effective support is that which helps parents to learn and achieve. Parents themselves are the best people to judge the effectiveness of support services. Families respond well to services which provide consistency and continuity in terms of staff support and resources.
- The trend is towards including parents with learning difficulties in generic, community-based services used by other parents, with additional specialist input only when necessary. Services need to be *family centred* (rather than parent or child only focused); emphasise *prevention* (rather than crisis intervention); emphasise parents' strengths; be tailored to the individual needs of each parent or family; be available long term and be flexible.
- Barriers to the development and maintenance of services include: limited funding; a lack of skills among professionals for assessing and supporting parents; negative attitudes about parents with learning difficulties; lack of coordination between children's and adult services.
- Most of the evidence available focuses on the experiences of parents with learning difficulties bringing up babies and young children. There is very little evidence around the experiences of such parents with older or teenage children.
- Parents with learning difficulties need information about services and entitlements that is accessible, in appropriate formats and locations, and communicated clearly to them.
- Professionals working in this field have a variety of information and training needs. Many professionals – including many children and family social workers and community learning disability nurses – do not feel properly equipped to work effectively with parents with learning difficulties.
- Multi-agency working is generally agreed to be the most fruitful way forward – but this needs to be very carefully organised to ensure consistency and continuity if many professionals are involved.
- Parents tend to be reluctant to approach statutory services for support because of fears of negative judgements on their parenting if they do so.
- The views and experiences of parents with learning difficulties themselves have only recently begun to be heard, and responded to, in the literature and elsewhere. (SCARE, 2005a; Llewellyn & McConnell, 2005; McGaw & Newman, 2005)

## Key Research on Families where a Parent has a Learning Difficulty

- A range of research projects have been undertaken in relation to families where a parent has a learning difficulty by Gwynnyth Llewellyn, David McConnell and colleagues at the University of Sydney, Australia. For details see: [www.afdsrc.org](http://www.afdsrc.org)
- For details of the research undertaken in Sheffield, England by Tim and Wendy Booth, including studies on parents with learning difficulties; growing up with parents with learning difficulties; advocacy support for parents with learning difficulties; supported learning for mothers with learning difficulties; parents with learning difficulties, child protection and the courts, see: [www.supported-parenting.com](http://www.supported-parenting.com)
- For the Social Care Access to Research Evidence briefing (1/14) on the available knowledge base on *Helping parents with learning disabilities in their role as parents*, go to: [www.scie.org.uk/publications/briefings](http://www.scie.org.uk/publications/briefings)

### 4. The views of parents with learning difficulties

The Baring Foundation initiative was grounded in the belief that parents with learning difficulties should have the same rights as other parents, and that they should be at the centre of all activities pursued within the Baring programme. Accordingly, a group of parents with learning difficulties were invited to act as consultants to this project.

Circles Network, who have been involved in supporting parents with learning difficulties through a range of initiatives (see Box later in chapter), passed on accessible information produced by the project to parents with learning difficulties in the Bristol area. Our expectation was that only a small number of parents would agree to participate as consultants.

Much to our surprise, the first meeting was attended by 13 parents with learning difficulties – nine mothers and four fathers, along with two of their children (including a six week old baby). The group represented a wide spread of parents, whose children ranged in age from six weeks to thirty years. All the parents – with the exception of the couple with the young baby – had had children taken into care at some time; some had not been allowed to see their children for over 15 years. One couple had their child taken into foster care while they were part of the group.

The group met three times during the project. Most people attended at least a part of all the sessions, which followed a regular pattern: listening to what had happened recently in each person's life and offering emotional support to each other. The two researchers would then seek advice from the group on the current or next stage of the project (for example, what to include in the questionnaire; how to interview other parents; issues and themes emerging from the project). Finally the group would have lunch together. The following key themes emerged:

## What helped

- Good supporters, who listened and did what was asked of them
- Good social workers, who helped with forms
- Circles Network (see Box) and Sure Start who were seen as offering good support: Sure Start had tips on looking after the baby, helping with the cleaning and what to do when families were not supported
- An assistant midwife who took the baby out to give a couple a break
- A coordinated multi-agency team. (The couple who had kept their new baby had a meeting once a month of everyone working with them, which meant that things were not continually repeated with different people. The child protection social worker came to this meeting which was felt to be helpful, not threatening, since he asked the couple what was worrying them and then helped them with it).

## What did not help

- Social workers from children's services, who were almost always mentioned in a negative way
- Children and family centres, which had been experienced as very intimidating: parents felt that they were being watched, with staff waiting for them to make mistakes
- Going away for assessment to a children and family centre, which meant the parents lost touch with all their own, trusted, community support just at the time when they were being expected to perform at their best.

## Difficult things

- All the parents had had problems with housing
- Depression was common
- Everyone feared going to court: some people felt it was secret and adversarial; they often felt uncertain about how decisions were made and could not understand the court and other legal papers
- Some people felt that the judge looked down on them or ignored them (but others found that the judges presiding over their case listened and were helpful)
- Professionals often seemed to forget that parents were still parents, even when their children had been taken into care or adopted.

## Other points

- Parents' experiences of their own extended families were varied – in some cases they were supportive, in others interfering or unhelpful

- Everyone agreed it was great being a parent – despite the enormous number of difficulties they confronted
- They all loved their children – and wanted the best for them.

## Circles Network: Family Empowerment Projects

Circles Network is a voluntary organisation working across the UK which is best known for its work in facilitating the establishment of 'circles of support' for vulnerable people. A circle of support is made up of individuals known to a particular person who meet together on a voluntary, unpaid, basis to help the person achieve their goals. Circles is also well known for its pioneering work in supporting parents with learning difficulties and their children, originally through its Crowley House project but now through its family empowerment projects.

Circles' Network works with disabled parents, including parents with learning difficulties, in six ways:

**Assessment.** Circles Network is engaged through a referral (or introduction, as they prefer to call them) from someone in the legal system, eg a solicitor or barrister, to undertake an assessment for a court hearing, of the parents' capacity and support needs. The Circles worker may be involved for 40-60 hours preparing an assessment, or person-centred plan which is funded through the legal system. This kind of assessment has a number of advantages over referral to a residential assessment centre, as it is usually difficult for parents with learning difficulties to transfer their learning, or to demonstrate their capacity, in an alien environment.

**Assessment/teaching.** A local social services department may refer/introduce a parent to Circles Network, as a result of anxiety that they are not fulfilling certain parenting criteria or other concerns, for example that their house is becoming very dirty or that their children are not being fed well. The Circles worker will undertake an assessment based on a person centred plan, but also engage in teaching or facilitation so that the parent can understand the information they need, or the tasks they have to perform, for example by devising some kind of pictorial calendar. This work will be funded by a social services department.

**Providing ongoing support on a one to one basis.** Again, this referral or introduction will be from the social services department to work with the family either in the community or at home, undertaking teaching or coaching. Input from the Circles worker will vary but might take the form of, for example, two to three hours' support for three days a week for six months, or longer.

**Developing a Circle of Support.** In addition to, or instead of, the above, the Circles worker may facilitate the development of a circle of support around the parent.

**Other help.** The Circles support worker will also be trying to support the parents' ability to be in control of what they need and to direct them to other sources of support, such as applying for direct payments.

**Family matters.** Circles is currently receiving funding from the DfES to develop a pack to support disabled parents, including parents with learning difficulties. The pack is being developed in association with disabled parents and includes a variety of helpful tools geared to support people in their parenting tasks.

For more information contact:

**Circles Network, Potsford Dam Farm  
Coventry Road, Cawston  
Rugby, Warwickshire, CV23, 9JP**

**Tel: 01788 816671  
Fax: 01788 816672  
Email: [info.circles@btconnect.com](mailto:info.circles@btconnect.com)**

## 5. This report

The report that follows is informed by the themes identified in the literature and those that emerged from our consultation with the parents' reference group. It is structured into three parts as follows:

- **Part 1** maps out the current services and supports for parents with learning difficulties, as revealed by our questionnaire (Chapter 2) and the issues faced by such parents and by the staff supporting them in their parenting role (Chapter 3).
- **Part 2** focusses on different elements of positive practice. Chapter 4 outlines the core themes underpinning the concept of 'parenting with support' and parents' experiences of it. Chapters 5 to 8 describe the wide range of strategies utilised by staff involved with parents with learning difficulties and their families: identifying parents with learning difficulties and helping them access appropriate support in pregnancy (Chapter 5); providing effective support to the family (Chapter 6); helping parents engage with other agencies, with advocacy and multi-agency support (Chapter 7); and child protection and the courts (Chapter 8).
- **Part 3** (Chapter 9) summarises key messages and conclusions from the project, with recommendations for developing positive practice on a wider scale in the future.

Wherever possible, examples of positive practice are included. In some places, these take the form of Boxes giving further information about some of the organisations and initiatives involved in supporting parents with learning difficulties and their children. The names of individuals (whether professionals or parents) and of some of the services involved with them, have been omitted or changed in some cases to protect identity.



# Chapter 2 What kinds of services are supporting parents with learning difficulties?

***Some people say that you don't deserve a baby and think that if you have learning difficulties you are stupid and will not be able to manage.***

(Parent with a learning difficulty)

## Introduction

This chapter focusses on the services (and staff) who responded to our web-based questionnaire. More details of the questionnaire and the way it was piloted and promoted are given in Appendix 1.

### 1. Agencies providing support to parents with learning difficulties

A wide range of agencies were involved in supporting parents with learning difficulties. These included community learning difficulties teams, other social services, learning difficulty or advocacy services, children's services (including Home-Start and Sure Start), national charities and health trusts or primary care trusts (see Table 1, Appendix 2). Other services represented included a family link service, a forensic psychology service, an independent living scheme, a direct payments service, a sports development agency and a People First group.

The services ranged in size from small organisations supporting fewer than 50 people (16) to organisations supporting more than 1,000 people each (3). Their primary focus was: adults with learning difficulties (60); parents with learning difficulties (8); vulnerable families (7); children (5); other (5). Only one response was received directly from a generic service but workers from mainstream services (eg midwifery) were included in the multi-agency teams supporting parents with learning difficulties (see Section 3 below).

The majority of agencies covered a specific geographical area of the UK, for example a local authority area. A small number of organisations covered a larger geographical region. Three agencies had a UK-wide remit while one organisation was a Scottish national charity working with and on behalf of people with learning difficulties.

Most of the services received some funding from social services (30), health (24) or both health and social services (25). Twelve services had funding from charities, five had funding from voluntary organisations and four were funded individually in relation to each family they were helping.

The charitable funders included: the Big Lottery, British Institute of Learning Disabilities (which distributes government funding to support advocacy schemes in England following the *Valuing People* White Paper) and the Children's Fund. These were supporting specialist parenting services and five of the advocacy organisations. One advocacy service was also partly funded by the Welsh Assembly.

Several of the services represented were funded from a combination of sources. Two respondents specifically mentioned their 'creative use of funding streams' and the use of a variety of statutory (including Sure Start), voluntary and charitable funding.

## Funding

The specialist team supporting parents with learning difficulties in North Tyneside has been awarded money from the Children's Fund to promote inclusion. Parents with learning difficulties are amongst the most socially isolated in a community and as result so are the children. The team was able to demonstrate that supporting the parents enables children to become more involved in their community and improve attendance at school.

## 2. The range of professionals involved in teams providing services for parents with learning difficulties

The majority of teams providing support to parents with learning difficulties included workers from a range of professional backgrounds and from different agencies. As one professional advocate pointed out:

***Each case varies in who helps/advises the parents. In cases where the parents have been in care themselves there is quite often a great number of people involved, due to past history with social services.***

Seventeen teams included social workers from children and family services as well as social workers from adult services. As Table 2 (Appendix 2) shows, mainstream health workers, like midwives (18) and health visitors (23) were also well represented.

Individual teams also included a family group conference facilitator, a counsellor, a crèche worker, a housing officer, art, drama and music therapists, and a behavioural nurse/therapist.

## 3. The priority given to supporting parents

The priority afforded to supporting parents with learning difficulties varied between respondents. In the case of seven services, their overall aim was to support parenting in vulnerable families generally. Only two workers in these services felt that specifically supporting parents with learning difficulty was a priority:

***Working with all parents is our priority, of which we recognise that parents with learning difficulties are a part, and require additional support.***

(Local Sure Start worker)

One worker recognised that parents with learning difficulties were not an explicit priority within their local Sure Start service:

***...purely due to the fact that there are few known parents with learning difficulties.***

(Local Sure Start worker)

This lack of awareness about parents with learning difficulties and their support needs is discussed further, in Chapters 3 and 4.

Within the services providing general support to adults with learning difficulties, two thirds of the workers felt that parenting was a priority within their service. Three workers specifically commented that parenting was becoming a priority for their learning difficulties services and that there appeared to be:

***A new acceptance that adult services have a responsibility to provide support for adults in their parenting role.***

One worker noted that they had been directed to support parents with a learning difficulty by their director of social services, while another commented:

***Managers are very keen to set up protocols for joint working with Children and Families.***

Many of the professionals who completed the questionnaire reported that they had been championing the need within their services to support adults with learning difficulties in their parenting role. This had come about for three reasons:

- Their personal interest in supporting adults with learning difficulties as parents
- In response to a 'contested case' where they felt parents were treated unfairly or not given a chance to show they could parent
- An increasing number of referrals.

In contrast, one third of the workers in services supporting adults with learning difficulties felt that supporting parents was *not* a priority within their service. The reasons given for this included:

- Supporting parenting was 'equally important along with the other important work'
- Workers responded to each referral individually and then prioritised the referral appropriately
- There was no specific funding for supporting parents
- Some workers felt that children's services should 'meet the demand'
- Staff already had a large caseload
- They did not wish to get involved in judicial proceedings:

***...there can also be a reluctance to take people [parents with learning difficulties] on because of the complexity of the work and the potential for court involvement.***

(Social worker in adult services)

## 4. The types of service provided to parents with learning difficulties

The agencies responding to the questionnaire were endeavouring to provide whatever support was necessary to parents with learning difficulties. As shown in Table 3 (Appendix 2) this support usually included:

- Emotional support (32 services provided counselling; 44 specifically supported parents with learning difficulties during judicial proceedings; 36 services continued to support parents after judicial proceedings, generally when their children had been removed)
- Education and skills training before and after the children were born
- Assessment of parents' needs in their own home and joint assessments with children's services
- Support in the family home
- Advocating with and for parents (17 advocates completed the questionnaire but a further 27 workers regarded advocating for parents as part of the support they provided)
- Help with direct payments.

Other (less commonly provided) support included general support on everyday living such as behavioural interventions or information about leisure, sex and housing. For more specialist help, including legal representation, parents were supported to work with the appropriate professional.

## 5. Assessing parents' support needs

Specialist parenting services used a wide range of assessment strategies, including observation of parents during a parenting course. One specialist parenting service listed the range of tools that might be used:

- *WAIS III – formal cognitive assessment*
- *Parent Assessment Manual (McGaw et al, 1998)*
- *Familywise pack*
- *community care assessment*
- *interview/observation*
- *daily living skills checklists*
- *informal tools eg pictures/photos/symbols as a basis for discussion*
- *Sex and the 3R's (McCarthy & Thompson, 1998)*
- *gathering information from others.*

Table 4 (Appendix 2) shows that the most commonly used form of assessment was the *Parent Assessment Manual* (McGaw et al, 1998).

Other assessment strategies used included: person-centred planning, health action planning, assessment of forensic history, implementation of the *Framework of Assessment for Children in Need and their Families* (DH, 2000) and a children's planning team's assessment tool. In addition two other parenting packs were used: *First Steps to Parenthood* (Young & Strouthos, 1998) and the *Familywise* pack (produced by One Plus One, [www.oneplusone.org.uk](http://www.oneplusone.org.uk)).

## 6. Assessing the needs of the children

The assessment of children's support needs was seen primarily as the responsibility of children and family services, although three adult teams responding to the questionnaire were supporting children and families as part of the *Framework of Assessment for Children in Need*. (Here parenting capacity forms one side of the assessment triangle, the other sides being the child's developmental needs and family and environmental factors; DH, 2000). A fourth team was seeking to work with the children and family service on these issues.

When agencies supporting parents with learning difficulties were involved in assessing children's needs, workers reported using a variety of strategies. These included: relying on their own skills; discussions with parents; parents' families and other workers; occupational therapy and speech and language assessment; as well as assessment at mother and baby units or family centres.

## 7. Referral routes

Parents with learning difficulties were referred to services by a wide range of other professionals including GPs, health visitors, occupational therapists, midwives, support workers and teachers (of their children) as well as, in one service, the police. One worker noted their team had received referrals from local circles of support and a supported housing service, while another service held drop-in sessions for parents with learning difficulties:

***Parents can be referred by anyone including self referrals. The main referrers tend to be social services, though referrals have been made by health, education, solicitors etc.***

(Occupational therapist)

Thirteen respondents reported that parents with learning difficulties were self-referring to services, on occasion because they had heard about them through word of mouth from other parents attending parenting groups.

## 8. Eligibility criteria

The majority of services (47) working specifically with adults or parents with learning difficulties had eligibility criteria relating to the adults' classification as having 'learning difficulties':

- Five services specified that the individuals' disability needed to have been present from childhood

- Two specified an IQ of less than 85
- Five specified an IQ of less than 70
- Five services combined the criterion of a learning difficulty with the criteria for *Fair Access to Care Services* (DH, 2002).

A number of respondents expressed concern about parents who were perceived to be 'too able' to receive support from learning disability services and would only be recognised as needing support when there was a crisis or a child protection issue arose (Morris, 2003; DfES, 2003a).

Only one of the services supporting vulnerable families had eligibility criteria related to the parents' IQ. In this service parents needed to have an IQ of 55-85 for intensive support, while other parents were eligible for more general support. In other services, the eligibility criteria focused on either the age of the child, a designated post code or the failure of other services to help bring about positive change.

Other respondents reported eligibility criteria that were appropriate to their particular services. For example, one direct payment service stated that the adult concerned had to be willing and able to have a direct payment, while another service (for which fees were charged) supported 'anyone facing social exclusion'.

## **9. The number of parents with learning difficulties supported by individual services**

Respondents were often unable to supply firm information about the numbers of parents with learning difficulties supported by their service or agency. This confirmed the consensus in the literature on the lack of precise information about the numbers of parents with learning difficulties in the population referred to in Chapter 1.

Of the 56 services whose responses stated the number of parents with learning difficulties they supported, nearly half (26) were supporting fewer than 10; 14 were supporting 11 to 20; 13 were supporting 21 to 50 and three were supporting more than 50 parents.

The seven services supporting vulnerable families were supporting between 20 and 300 parents each, of whom between three and 50 were reported to have learning difficulties.

## **10. The number of families supported by individual workers**

Just over half of the respondents (36) were supporting between one and five families; 25 were supporting six or more families, while one worker was supporting 27 families (Table 5, Appendix 2).

The caseloads of workers in specialist teams were generally higher, reflecting their primary focus on parents with learning difficulties, and ranged from seven to 27 parents.

## 11. The specific training received by professionals

Just under half of the workers who responded to the question (42 out of 76) had had specific training for working with parents with learning difficulties. One respondent was upfront in recognising they had received:

***No specific training. I am just pulling together my past training and experience in related fields.***

(Advocate)

The training received varied considerably. Most frequently it included an understanding of child protection, as well as the situation for parents with learning difficulties and their support needs. In five instances the training on parents' needs was provided by parents with learning difficulties themselves (see Table 6, Appendix 2). Other training (attended by fewer than four workers) included the development of good practice in supporting parents with learning difficulties.

Workers in the eight specialist parenting services had far more comprehensive training than other respondents. One worker commented that she had been on more training events than she could remember, while another spoke of intensive induction and shadowing a colleague before taking up her role.

## 12. The training professionals wanted

The training most often wanted by respondents was on child protection (10 workers) and the Children Act/Child Care Law (10 workers), with a few mentioning training around abuse and risk assessment. One worker specifically wanted training around the Adoption and Children Act and how its provisions would impact on parents with learning difficulties (see Chapter 3, Section 9 below).

Respondents did not express a consistent desire for specific types of training but stressed the importance of undertaking joint training with other services. They felt this would enable them to understand each other's roles, share expertise, and develop trust, so that they could work more closely and supportively in the future. Some workers commented that they would like information about local and regional multi-agency networks and other services that were available locally.

The range of desirable additional training suggested (each by up to five workers) included the following:

- **Understanding and educating parents**

- Understanding the needs of parents with learning difficulties. (One service wanted all its support staff to undertake a Learning Disability Assessment Framework (LDAF) certificate in working with parents with learning difficulties. Two workers suggested that awareness training on the needs of parents with learning difficulties should be presented by such parents).
- Coaching/teaching parents
- Communication with adults with learning difficulties

- **Assessing parents' support needs**

- Parenting skills assessments (including the use of the *Parent Assessment Manual*, McGaw et al, 1998)
- Community care assessments
- *Framework for Assessment of Children in Need* (DH, 2000)
- Advocacy

- **Providing support for parenting**

- Parents' rights
- Good practice models for supporting parents with learning difficulties
- Use of a multi-agency protocol
- Family therapy training
- Child care and development
- Emotional needs of children
- Independence and integration of people with learning difficulties.

The workers in more generic services, such as Sure Start, Home-Start and Barnardo's family centres, stressed the need for teaching/coaching skills.

Our study preceded the implementation of the *Common Assessment Framework* (CAF), introduced following the Green Paper *Every Child Matters* (DfES, 2003a). The CAF is designed to ensure a shared assessment is undertaken where there are potential concerns about a child's wellbeing. It is being piloted in selected areas and evaluated before being rolled out nationally (DfES, 2005a&b). This, along with the information sharing (IS) index and integrated children's systems (electronic record systems being developed as part of the *Every Child Matters: Change for Children Programme in England*), are clearly further areas where the multiple professionals involved in supporting parents with learning difficulties and their families will require training in the near future. (See DfES, 2005b & c for further details).

### **13. Support for staff**

The majority of workers who responded were supported in their work with parents with learning difficulties through: informal discussions with colleagues (61), supervision (58) or team meetings (48). Ten workers also had a mentor. Other forms of support included: specific support regarding child protection, clinical supervision, contact with other organisations and projects supporting parents, as well as attendance at parenting meetings and forums. Several respondents reported that they were supported in a variety of ways:

***A multi-agency group meets and is working on a joint-working protocol, a dedicated resource library and a 'professionals' meeting which will be chaired by experts/specialists, where people working with***

***parents with learning difficulties can discuss scenarios and receive support and guidance.***

(Advocate)

## **14. Working with other agencies and professionals**

Twenty-nine of the services supporting parents with learning difficulties were employing specific strategies to enhance multi-agency working. Workers frequently attended local network groups (26), steering groups (20), round table meetings (19) and advice groups (7). Individual workers were also attending child or adult protection interest groups and other relevant internal working groups.

Individual services had also been involved in the development of regional parenting networks, had ensured that their local intranet included information on working with parents with learning difficulties and had organised workshops and co-training with other agencies.

In addition, workers were attending Looked After Children Reviews, Child Protection core group meetings, professional meetings, and family support meetings in relation to particular families' support needs.

In nine areas some form of multi-agency strategy/protocol or care pathway had been, or was in the process of being, developed around supporting parents with learning difficulties. In another area, a joint assessment policy had been developed for disabled parents, which included parents with learning difficulties.

Respondents identified various benefits of joint working such as: developing a deeper understanding of the parents' situation; developing positive relationships; keyworking and the ability to offer coordinated yet flexible services. (For more information on multi-agency working see Chapter 7).

### **Summary**

- A wide range of professionals and agencies, were supporting parents with learning difficulties, including: services for adults with learning difficulties, specialist services for parents with learning difficulties, services supporting vulnerable families and voluntary organisations.
- Professionals were generally supporting parents with learning difficulties as part of small teams which included: community nurses, psychologists, speech and language therapists, adult social workers and support workers, health visitors, midwives and advocates.  
The make up of the team varied according to the family's need. Teams supporting a family often included workers concerned with protecting the children of the family, such as children and family social workers or the Children's Guardian.
- Supporting *parents* with learning difficulties was becoming a priority among services supporting adults with learning difficulties generally. However, a third of workers did not see supporting parents with learning difficulties as a priority.
- Agencies supporting parents with learning difficulties were providing a wide range of services, including: assessment of support needs, support in the home, skills training, emotional support for parents (particularly through the child protection and judicial processes) and advocacy for parents.

- Various assessments were used to ascertain parents' support needs. The most frequently used was the *Parent Assessment Manual* (McGaw et al, 1998). Children's support needs were generally assessed by children and family services.
- Parents were referred to support services by a wide range of professionals. Some parents also self-referred.
- Eligibility criteria in services supporting people with learning difficulties related to their learning difficulty 'label'. In services for vulnerable families eligibility criteria mainly related to the ages of their children.
- Many of the professionals who completed the questionnaire did not know how many parents with learning difficulties their agency was supporting.
- The training desired by professionals included: child protection, training by parents with learning difficulties about their needs, good practice in assessing support needs and strategies to support parenting. Joint training with other services and professionals was seen as a route to mutual understanding and more harmonious working.
- Only half of the workers supporting parents with learning difficulties had undertaken specific training.
- Workers in services supporting parents with learning difficulties were supported themselves through informal discussions, supervision, team meetings and attendance at relevant interest groups.

# Chapter 3 The issues faced by parents with learning difficulties and the workers who support them

***They think that because we have learning difficulties we can't look after our kids.***

(Parent with learning difficulties)

## Introduction

This chapter describes the issues faced by parents with learning difficulties and the professionals endeavouring to support them. The web-based questionnaire asked professionals if there were any factors, including the attitudes of other people, which hindered their work with parents. Their responses confirmed many previous research findings (eg Booth, 2000; McGaw & Newman, 2005; Morgan & Goff, 2004), that parents were very likely to be discriminated against and encountered:

- Negative stereotypes and assumptions
- Lack of awareness about people with learning difficulties
- Fixed ideas about parenting and what should happen to children
- Lack of consistency and clarity on what constitutes 'good' parenting
- Lack of engagement with children's services
- Late or crisis point referrals
- Insufficient time and resources.

## 1. Negative stereotypes and assumptions

Professionals supporting parents with learning difficulties often said that staff in other services – who had no specialist experience of working with adults with learning difficulties – presumed that people with learning difficulties:

- Were incompetent and never going to be 'good enough parents'
- Would be unable to understand their children's needs
- Would be unable to learn skills quickly enough to meet their child's developmental needs:

***There is, in general, a negative attitude from many professionals involved with these parents. That having a learning disability prevents them from being 'good enough' parents. That the parents will not be able to learn to parent more effectively, or that it will take more time and children cannot wait. Also that giving families additional support will be prohibitively expensive.***

(Advocate)

These professionals felt that such negative perceptions prevented parents from parenting to the best of their ability:

***Parents are often very disempowered by services and the attitudes of staff within services. I have found this to have a negative effect on parents' ability to be good enough parents.***

(Community nurse)

## **2. Lack of awareness of parents with learning difficulties and their support needs**

Professionals supporting parents with learning difficulties were aware that most staff in family support and child protection services did not have experience of working with people with learning difficulties. As a result, they did not understand what the impact of having a learning difficulty on an individual might be. It also meant they lacked relevant skills, for example, in understanding parents' communication or learning support needs, and, as a result, becoming 'frustrated' when working with them. Such failures in communication undermined parents' ability to respond positively to staff suggestions. (This is discussed further in Section 5 below).

## **3. Fixed ideas about parenting and what should happen to children**

Some respondents felt that other staff, particularly those working in child protection rather than family support, had fixed ideas about what should happen to the children of parents with learning difficulties. They also felt that children and family social workers wanted to ensure a 'concrete outcome' for children which would prevent them from being exposed to *any* level of risk. Although the Children Act indicates that children should be supported within their family whenever possible, staff supporting parents with learning difficulties felt that child and family social workers lacked the capacity to see the bigger picture, and how parents with learning difficulties could be supported:

***Children's services do not have a concept of ongoing support to mitigate the effects of a disability. Neither do they have mechanisms or funds to mitigate this... [They] give the appearance of just wanting to get the child placed with other parents as soon as possible.***

(Psychologist)

Compounding this, professionals supporting parents with learning difficulties felt that these parents were, unhelpfully, expected to be 'perfect parents' and to meet 'impossibly high standards'. In common with findings from McConnell & Llewellyn (2002) and Sellars (2002) these 'perfect standards' were felt to be of a much higher level than those applied to non-disabled parents.

A small number of staff also felt that parents with learning difficulties did not get the support other families would receive in the event of a crisis or unfortunate life-event:

***How other parents known to social services receive information to access support and help systems or assistance to deal with issues doesn't seem to happen to parents with a learning difficulty – in one case a mum's distraction from learning new skills because of benefit, housing and relationship problems was given as a reason why she wouldn't be able to change her parenting skills to meet the needs of her daughter.***

(Advocate)

Some staff felt that parents with learning difficulties were 'doubly discriminated against' if they themselves had had an abusive or neglectful background, or were encountering difficult life-events:

***They are not allowed to have unfortunate life-events, they are not allowed to have an abusive partner for instance – this is a failure to protect the child.***

(Psychologist)

#### **4. Lack of consistency and clarity on what constitutes 'good parenting'**

***The social worker says, 'Don't cuddle the baby too much'. The foster carer says, 'You can't love a baby too much'.***

(Parent with learning difficulties)

Professionals supporting parents with learning difficulties said that a lack of clarity around what constituted 'good parenting' contributed to parents' lack of confidence in their skills and in their ability to prove that they were 'good enough' parents. These workers recognised that, as parenting is not an 'exact science', each person coming into contact with parents with learning difficulties had their own concept of 'good parenting', often related to personal experience.

As a result, parents with learning difficulties often did not know what standards they should be working towards. This confusion ranged from simple issues such as whether a dummy was acceptable to whether pursuing their own personal development was appropriate. One worker noted that a mum had been both praised and criticised by different staff for leaving her child with her mother one day a week in order to attend college.

This issue was of particular importance to parents when their social worker from child and family services changed, requiring the parent to form a new relationship and perhaps conform to new values around parenting:

***Families can often move through three or four teams in a space of three or four months, with frequent changes of social workers or being unallocated for periods of time. The direction of the case is influenced by the individual social worker and leaves the parent feeling very confused.***

(Social worker working with adults with learning difficulties)

#### **5. Parents' lack of engagement with children and family services**

Parents with learning difficulties involved in the project advisory group and those who took part in individual and group interviews confirmed each of the themes discussed by workers above. They felt that services concerned with the welfare of their child:

- Did not understand people with learning difficulties
- 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

***...pushed aside once the child is gone, you are no longer an issue.***  
(Parent with learning difficulties)

The parents' anxiety and fear often resulted in them taking a deliberate stance against services and workers that they felt were threatening their family. This was particularly the case when they had had children removed in the past. This seemingly adversarial position, and disengagement from children and family services, could subsequently feed into children and family services' concerns about their parenting ability.

***They hear what they want to hear, they don't listen to your side. They don't understand what you are saying. They are only interested in taking the kids. They judge you too quickly – that's what hurts the most.***

***They make us look small... put you down... twist what you say.***

***Social workers assume you can't do it. They talk about your history and baggage, they don't let you change... They use the same evidence against you ten years later.***

***If your child has been taken away, professionals assume your next one needs to go.***

***They accuse you of things, if you do something wrong they make a big issue, make it look like you did it on purpose.***

***If your child has to go to hospital ill, you feel you've done something wrong. You feel judged again.***

The parents in this study felt that, in the absence of support, their attempts to speak up for themselves were also used against them:

***You can't have a go at them. They say you are negative and you are a bad mother.***

Parents felt other people judged them for even having a social worker, and said that involvement with children and family social workers was belittling, stressful and confusing. In the week following the birth of a baby, a parent with learning difficulties could easily meet eight professionals, if the baby was staying with them, and an additional six if the case was 'going to court'. The stress of contact with so many professionals was increased by the frequent turnover of staff in children and family services, with the result that parents, paradoxically, felt bereft of support:

***Social worker changed, never knew who social worker was.  
You feel deserted... like being on an island with sharks all around.***

However, at the time that this study took place, all of the parents involved in the discussions whose children were living with them, were receiving support from adult services, special parenting services, or services for vulnerable families. Workers in these services were acting as interpreters, or mediators, and supporting parents to engage with children and family services, to break the vicious cycle which has developed in their interactions with services and to prove that they could, with support, be 'good enough' parents. (For more on helping parents engage with other services, see Chapter 7).

## **6. Late or crisis point referrals**

Respondents supporting parents with learning difficulties felt that the lack of awareness in other services was responsible for the late referral, frequently at crisis point, to adult and specialist support services:

***Too many of our parents are referred only at the point at which Child Protection team have decided to place the matter before the court. At this point they receive few services geared to assist them to become more effective parents. Hearing the chronology of these parents' problems leaves me feeling that if they were referred earlier it might have been possible to gain them access to effective services which helped them keep their children.***

(Advocate)

This was exacerbated by the fact, that many of the parents with learning difficulties who became known to children and family services, had until that point, not been in contact with traditional learning difficulty services (as recognised by DfES, 2003b).

## **7. Lack of time, resources and service coordination**

Many workers recognised that lack of resources inhibited the provision of support for parents with learning difficulties. A lack of consistency and coordination between services had a negative impact on the potential of the services that were provided.

## **8. Concerns about the implications of the Adoption and Children Act 2002**

Three respondents to the web questionnaire (echoing Booth, 2003) specifically raised concerns that pressures for children to be placed for adoption at an early age would be increased by the implementation of the provisions of the Adoption and Children Act 2002.

***...pressure to get the child adopted at a very early age, the earlier the better really for the child, two or three years... they [Child and Family Social Workers] are the ones who sadly have to make the decision whether parents are going to come around or not ...it's really difficult, especially with the new Adoption Act coming in and pushing the targets.***

(Social worker working with adults with learning difficulties)

## Summary

Respondents reported a range of barriers to the provision of appropriate support to parents, including negative, or stereotypical, attitudes about parents with learning difficulties. It was felt that staff in services whose primary focus was *not* people with learning difficulties:

- Did not fully understand the impact of having learning difficulties on individual parents' lives
- Had fixed ideas about what should happen to the children of parents with learning difficulties and wanted a 'concrete outcome' for children which removed all risk – this might mean them being placed away from the family
- Expected parents with learning difficulties to be 'perfect parents' and had extremely high expectations of them
- Had differing concepts of parenting against which parents were assessed
- Did not give parents with learning difficulties the space to experience unfortunate life events before intervening, and did not provide the support other parents received when facing difficult circumstances.

Other issues inhibiting the provision of positive support included:

- Parents' disengagement from services because they felt that staff had a negative view of them and 'wanted to take their children away'
- Referrals to support services which were too late to be of optimum use
- A lack of time, resources and coordination.

## Chapter 4 Parenting with support

***Let's try a new way of doing it... giving parents a chance to show they can do it.***

(Community nurse working with parents with learning difficulties)

### Introduction

Staff in services which supported adults with learning difficulties were concerned to ensure that parents were given the chance to prove that they could 'parent with support' and be 'good enough' parents. The concept of 'good enough' parenting (McConnell & Llewellyn, 2002; McBrien & Power, 2002; Sheerin, 1998; Swain & Cameron, 2003) was explained by one respondent like this:

***That people with a learning difficulty can be 'good enough' parents, but may need more support and time to learn new skills than parents without a learning disability. Parents with a learning difficulty are disabled people in their own right and should be eligible for resources/support when needed, to assist them in their role as parent.***

(Advocate)

It was recognised that parents would need ongoing support to help them parent to the best of their ability:

***We know they have a learning difficulty. 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)

Professionals involved in services supporting adults with learning difficulties and in specialist parenting services were concerned to ensure that children's welfare was protected. As they saw it, this was best done by helping the parents to understand what was required of them to fulfil their responsibilities towards their children and to care for them to the best of their ability.

### 1. Parenting with support: core themes

We have grouped the different elements of positive practice uncovered by the study into three areas:

- Raising awareness of parents with learning difficulties and their support needs
- Developing multi-professional and multi-agency support for parents with learning difficulties and their families
- Empowering parents with learning difficulties.

We have broken down each of these into more specific examples. Some of these may seem obvious, but the evidence from our study indicates that knowledge is unevenly distributed amongst all the different professionals who may be involved in supporting parents with learning difficulties and their children, so that stating what is obvious to some may be very useful to others.

- **Raising awareness about parents with learning difficulties and their support needs**

Those involved in the study were adopting a range of strategies to raise awareness amongst other professionals and agencies about parents with learning difficulties, their support needs and the services available. They were networking widely and setting up, or attending, multi-agency groups focussing on supporting parents with learning difficulties (see Box). They were also participating in groups with a wider focus, where they could raise issues concerning parents. They were developing leaflets about local services and producing information packs for staff in other services on how to identify and support parents with learning difficulties. They were also supporting parents with learning difficulties to attend mainstream groups and co-facilitating classes (such as antenatal groups) with other, generic, professionals, like midwives.

### Setting up Multi-agency Groups

*As a result of working together on the multi-agency group, attitudes towards parents have become noticeably more positive and there is far more effective communication between all professionals so that we are now giving parents consistent advice and support.*

(Psychologist)

Overall, these professionals were trying to act as a source of expertise to those in other services, including offering training to them, often with parents with learning difficulties as co-trainers.

- **Developing multi-professional and multi-agency support for parents with learning difficulties**

Professionals and parents in the study were united in the view that coordinated, multi-professional, and multi-agency, working was key to maximising the positive impact of different services on the lives of parents with learning difficulties and their families. Successful working of this kind depended on eight key ingredients:

- Use of a keyworker system to coordinate support to parents (see Box)
- Honesty and ongoing communication between all workers involved
- Understanding of individual professional roles and their boundaries
- Clarity and agreement on what constituted good enough parenting for individual families
- Shared goals and attitudes developed through joint training

- The development of joint protocols, policies and pathways for supporting parents with learning difficulties
- Training in understanding parents with learning difficulties for workers whose experience was in protecting children
- Training and support in child protection procedures for workers whose experience was in supporting adults with learning difficulties.

## What is Keyworking?

Keyworking systems aim to avoid inconsistency, duplication, gaps and confusion in the delivery of services, for professionals and service users alike. A named professional is identified as the key (or link) worker for a particular individual or family. In the case of a parent with learning difficulties, the keyworker would be responsible for ensuring the coordination of services and support to the family, and for effective communication between the different professionals involved, and between them and the parent(s) concerned.

More information on keyworking can be found on the website of Care Coordination Network UK, which exists to promote keyworking particularly for families with disabled children.

**Website: [www.ccnu.org.uk](http://www.ccnu.org.uk)**

(See Chapter 7 for more detailed information on multi-professional and multi-agency working to support parents with learning difficulties).

- **Empowering parents with learning difficulties**

In order to empower parents with learning difficulties, professionals and others were clear that they needed to work on a number of different fronts simultaneously.

First, they needed to ensure parents had access to easy to understand information about all aspects of parenting – from the choice whether to have children, to the skills and knowledge required at different stages to bring up their children appropriately, the services and supports available to them and about child protection procedures and the judicial process, if necessary.

Second, they needed to help parents understand (and respond positively to) the support they were offered. This meant trying to ensure, a consistency of approach between different professionals, clarity about each professional's role and responsibilities and honesty about the professionals' expectations of the parents. Parents needed to understand their responsibilities and what was required of them.

Third, it was important to make sure that the skills and knowledge parents already had were recognised through competency-based assessment, and competency-building support. Parents needed workers to praise their achievements, encourage them to use their own skills and understanding, and to share their skills and experiences with other parents.

Fourth, parents needed support to develop their skills, according to the advice given by key professionals, such as midwives, health visitors and children and families teams. This required clarity and consistency between different workers in the way skills were broken down and taught. It also needed creativity in adapting mainstream parenting materials for use with groups of parents with learning difficulties and in the way skills were taught to individual parents, including the development of tailored resources and materials.

Fifth, professionals needed to help parents to have a voice by listening to, and respecting, their views and perspective, through independent advocates (particularly in child protection or judicial

processes) and by keeping parents' views central when their support network included members of their family.

Finally, professionals could help to reduce the stress parents experienced by providing time and support to prepare for meetings and court appearances, supporting them at meetings, helping them to overcome issues in their lives which inhibited their ability to parent to the best of their ability and by providing ongoing support if their children were removed.

Further details and examples of positive practice in all aspects of enabling adults with learning difficulties to 'parent with support' are given in the chapters that follow.

## **What Helps People with Learning Difficulties be Good Parents?**

The following list was compiled by The National Gathering of Parents with Learning Disabilities held in January 2005:

- Accessible information about you and your baby's health, and 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)

## 2. The experiences of parents with learning difficulties

The parents supported by the services visited as part of the study were very positive about the support provided by adult learning difficulties teams, specialist parenting services and, in one area, Sure Start. One full-time father specifically described the way in which services were coordinated so that the support they received was consistent:

***We have a meeting once a month of everyone [7 or 8 people] working with the baby.***

This meeting was attended by the child protection social worker, who:

***...asks what worries us and helps us. He doesn't use it against us.***

All the parents spoke warmly of the professionals supporting them. They particularly appreciated staff who supported them in doing things for themselves. They spoke about getting help with daily routines, cooking, budgeting and cleaning their homes. In these instances, staff 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 they became more confident in their skills.

Parents said that professionals supporting them had helped to bridge the gap between them and children and family services, by supporting them in meetings and helping them to understand what these services were asking of them. As a consequence of this 'really good support', which usually included opportunities to phone for help when needed, one mother recognised that:

***I was a lot more tensed up than now... now I'm a lot more relaxed.***

All the parents that took part in the study had a unique story to tell. Here we include extracts from the stories of Bethany, Rob and Kylie, and Fiona, told primarily from their perspective.

### Bethany's story

Bethany has a four year old disabled daughter. She described herself as an experienced babysitter for her six nieces and nephews. She herself has some hearing loss and difficulty in understanding 'anything on paper'. She said she had been 'discovered' by a community nurse, Alison, who 'stepped in' during a meeting when her daughter was less than a year old:

***If Alison hadn't spotted me I wouldn't have a child now.***

Bethany said that before she met Alison she had been struggling with filling out forms, had lost her house and ended up living miles away from her mother. Children and family services had become involved. Bethany felt they were 'intimidating' and were not trained to work with people with learning difficulties. She said that one social worker had:

***...told me I was a bad mum... they talk to you like you are a two year old, treat you like a child.***

In contrast, Bethany felt that Alison was 'brilliant' and had done a lot to support her. Alison had helped her move closer to her mum, supported her in going to appointments, particularly for a digital hearing aid for herself, and for speech therapy for her daughter. Bethany was no longer in contact with children and family services, but received ongoing support from the community learning difficulties team and attended a parenting group.

### **Rob and Kylie's story** (as told by Rob)

Rob and Kylie had been together for many years and had already had two children taken away from them. They were bringing up their daughter April with support from services. Rob and Kylie talked about their deep commitment to April; they wanted to ensure that she had the best upbringing possible:

***Me and Kylie have been watching April grow up. We had a nice Christmas with her... now just getting safety things for her – fire guards and things... enjoying her grow up. If you've got kids you should treasure them, you don't know what you've got until it's gone... It means everything to us... We're not making any more mistakes.***

At the time of interview Rob felt that the family was well supported by 'social services':

***...got a nice social worker. She does what you ask. We get proper support in what to do.***

He felt the adult social worker:

***...feels we will be successful, trusts in me and Kylie.***

This social worker was supporting them through court proceedings and was helping them to get a holiday after the court case was over. April was at this time subject to an interim care order, which Rob viewed positively as it enabled them to get support.

Rob and Kylie were also supported by a voluntary organisation, which had:

***...helped me and Kylie, not judging us, helping us to do things with April. They explain it better than other people do.***

Rob suffered from anxiety and panic attacks and had support from a psychologist who, he felt, was there for him, rather than just to make sure the baby was okay. He felt that the psychologist:

***...listens to me... No-one else knows what I tell him. He has helped with lots of stuff. I'd recommend him, he listens. He just waits for you to tell him stuff, then he gives advice.***

Rob was still very angry about the way in which he felt they had been treated by services in the past. He had wanted to go to the newspapers with their story but felt that this would go against them when they had another child.

**Fiona's story** (as told by Fiona and the children and families social worker responsible for her children's welfare)

Fiona is a mother with learning difficulties. She also has mental health support needs. We were told she had experienced a very difficult childhood. Fiona had been known to social services for over 20 years and four of her children had already been removed. Fiona's two youngest children lived with her: Eleanor, aged nine and Sarah, one. Fiona had brought up Eleanor, her fifth child, for six years on her own before coming back into contact with social services and spending time at an assessment centre on the birth of her youngest child, Sarah.

Fiona said:

***I wouldn't work with Barbara [community nurse] because I didn't want to work with anybody, because last time I had the children they got taken away. So I wouldn't work with any of them... I didn't trust them. I didn't believe them... But I thought, this time I've got to do it and see how it works out. I thought I would lose her because I was on my own and I couldn't cook.***

After the involvement of the community learning difficulties team (CLDT) who worked with Fiona providing frequent visits and 'positive support', the children and family social worker said that:

***There was a real shift and she was starting to work well with us.***

The community learning difficulties team supported Fiona to get appropriate medical attention for her mental health support needs, to get out of debt and to refuse loans from loan sharks who were pressuring her. She also received an extensive package of support from the community learning difficulties team with Barbara acting as her key worker and supporting her through the judicial process. Fiona said:

***Barbara helps me the most, because I'd ring Barbara up when Eleanor is playing me up. She [Eleanor] kept saying she was poorly, she had a headache and I rang Barbara up and she came round and picked her up and took her to school.***

***You know like you're trying to say something to somebody on the phone and you get all confused. You tell Barbara and she'll help you. She went to the doctor's with me one day. If I didn't have support I wouldn't be able to do this because I used to lose my temper a lot and get violent.***

***Barbara went to court with me and Barbara wrote everything down.***

The children and families social worker felt that the support Fiona had received really had made a significant and positive difference:

***I can't speak highly enough of the CLDT team and the support that has been put in is phenomenal. I have no doubt whatsoever that if the CLDT team hadn't been involved with the case both of these children would not be with their family.***

The social worker was reassured that appropriate 'safeguards' were in place – the children were subject to a care order, there was a care plan in place and a high level of monitoring via the community learning difficulties team had been established. The community nurse was Fiona's keyworker and her main professional support, while a support worker supported Fiona in the home. Fiona's youngest daughter also had day care.

The social worker felt that working closely with the community learning difficulties team had resulted in:

***...a system that works and we [Children and Families] are withdrawn but we know exactly what is going on and have very good communication links.***

Fiona recognised that she had to continue working with services. She knew that otherwise her youngest children could also be taken away at any time, saying that:

***Social workers have all the rights.***

### **'Valuing Families' in Leicestershire**

In Leicestershire the Family Welfare Association (FWA) has been funded by the Children's Fund to run a specialist support service for families where a parent has a learning difficulty: the 'Valuing Families' service. This is part of the FWA's wider 'Building Bridges' initiative which works with whole families, across traditional service divides. (Most of the other local services within this initiative focus on families where parents have a mental health support need).

Parents in Leicestershire can either self refer to 'Valuing Families' or be referred by a relevant professional. About fifteen families are supported by the service at any one time via family support workers, who work with each family in their own homes and local areas. The staff work to meet the needs of the whole family - parents and children. For example, they help families to establish routines, they accompany them to appointments (and remind them beforehand!), they help parents to manage their children's behaviour and they ensure they have a healthy diet.

For more information contact:

**Richard Desjardins**  
**Tel: 0116 255 3738**

## Summary

- 'Parenting with support' meant that parents with learning difficulties could often be 'good enough' parents, when provided with the ongoing emotional and practical support they needed
- The concept of 'parenting with support' underpinned the way in which professionals were supporting parents with learning difficulties and providing appropriate services. It had three elements:
  - Raising awareness of parents with learning difficulties and their support needs
  - Developing multi-professional and multi-agency support for parents and their families
  - Empowering parents with learning difficulties
- 'Parenting with support' could make the cycle of parental interaction with services positive, empowering and confidence building through the provision of clear, consistent, creative and appropriate support
- Parents in the services we visited had positive relationships with the workers supporting them to parent
- These positive experiences resulted in a reduction in their stress, improved interaction with staff from children and family services and more effective parenting
- These parents were receiving consistent positive support at the times when they needed it. This enabled them to overcome other issues in their lives which were impacting on their ability to be 'good enough' parents.



# Chapter 5 Identifying parents with learning difficulties and providing appropriate support in pregnancy

***We want to be involved as early as possible***

(Community Nurse)

## Introduction

This chapter focuses on the importance of identifying parents with learning difficulties, and making appropriate help available to them as early as possible – including at the pre-pregnancy and antenatal stage.

### 1. Identifying parents with learning difficulties

Many parents with learning difficulties have not previously been in contact with services. This means that many of the professionals in generic services who come into contact with them as *parents* have little or no understanding of their potential support needs as *people with learning difficulties* (Green & Vetere, 2002).

Llewellyn et al (1999) highlighted the need for mainstream services to be better equipped to identify and support parents with learning difficulties. Professionals in our study were using the following strategies to raise awareness:

- Producing leaflets describing the support available from local services
- Proactive networking with a wide range of professionals, including solicitors and health workers
- Holding information days for parents and other staff
- Attending relevant groups and forums
- Providing training
- Prompting discussion in multi-agency groups to ‘explore the possibility that learning difficulties may be present’
- Developing a clear protocol/pathway/referral process, to be explicitly shared with staff in other agencies.

### 2. Tools for identifying if parents have a learning difficulty

In a number of areas tools have been developed to help staff identify whether a parent has a learning difficulty. For example:

***A workbook specially designed by the multi-disciplinary group to support a range of staff to identify a ‘vulnerable’ parent and which teams they should contact for support.***

(Psychologist)

The *Sanderson Screening Tool* was designed to enable non-psychologists to carry out a brief assessment with parents with suspected learning difficulties, to indicate whether a referral to clinical psychology services is necessary. Developed for health visitors, midwives, social workers and other professionals, the tool is also referred to as the STRAP-LD (Screening Tool Relating to the Assessment of Parents with suspected Learning Difficulties) and includes asking the adult to read a passage. Scores are provided for the number of mistakes made. The adult is then asked eight questions about the information in the passage. The tool should then be returned to the psychology department which developed it who advise whether the scores indicate learning disability (Hames & English, undated; McDonnell & Hames, 2005).

In another area, a pack had been developed to help midwives identify parents with learning difficulties. It contains: information about the definition and nature of 'learning difficulties'; a tool to assist identification of parents with learning difficulties; the pathway for accessing services and an agency referral form.

### **3. Training and support for professionals in identifying parents with learning difficulties**

Professionals supporting parents with learning difficulties recognised that generic staff need support if they are to be confident even about broaching the issue of whether adults they are in contact with have a learning difficulty:

***Referrers can be reluctant to label people with learning difficulties.***

(Community Nurse)

They could be 'embarrassed' and fear causing offence because of the 'stigma' attached to the 'learning difficulties' label.

Generic staff need to feel confident that they know how to communicate appropriately and sensitively when identifying parents with learning difficulties, and that support is available from relevant agencies. In a number of areas training was freely available and parents with learning difficulties were generally involved in providing this training.

One psychologist described the main components of the awareness training she co-presented to other staff with parents from her service's parenting group as follows:

- What is a learning difficulty? Looking at stereotypes
- What are the issues regarding parenting by adults with learning difficulties and how can the difficulties be addressed, so that the parents can 'keep' their children?
- How do adults with learning difficulties learn best?
- How can information be provided to adults with learning difficulties?
- How can adults with learning difficulties be supported in their parenting?

A recent Mencap project provides free training for people supporting parents with learning difficulties. This training *Making the difference* (Mencap, 2005) focuses on:

- What is a learning disability?
- The role of the parent

- The role of the volunteer
- The reality of having a learning disability
- Disclosing concerns
- Professional/friend; attachment/detachment
- Supporting parents with a learning disability.

Similar training, along with visits to other services, has been used by a number of agencies so that services have an understanding of the care pathway for them:

***Having and using a protocol has helped. LD [learning difficulty] nurses have made links with local health visitors and midwives. We have made visits to children and families social workers to talk about our services.***

(Community nurse)

(See Chapter 2, Sections 11-12 for more information about the training professionals had received or wanted.)

#### **4. Pre-pregnancy advice**

***We have a stock of accessible booklets about sex, sexual health and health issues.***

(Advocacy service)

The provision of appropriate accessible information is a key strategy in supporting adults with learning difficulties to understand, and make choices about, whether they want to become parents, hence CHANGE's publication *Planning a Baby* (Affleck, undated).

Professionals involved in the study were concerned that adults with learning difficulties should be supported to understand the information provided and the choices available, where possible by an advocate. Providing this support themselves was very time consuming for staff.

In one area, the implications of parenthood were explained to students while they were still at special school (cf. English, 2000). Here, a parents' group ran a workshop each year at a local special school, which introduced students not only to the joys of parenthood, but also to the difficulties.

#### **5. Antenatal support**

If adults decide to become parents, then contact with maternity services is advised from as early as possible. Professionals supporting parents with learning difficulties suggested that pro-active one-to-one work with parents should begin in the sixteenth week of pregnancy, with the community nurse supporting parents to understand the information provided by the midwife and to develop the required baby care and other skills. Parents also needed support to attend, often over-subscribed, generic antenatal classes, although they might feel, like some parents in this study, that they did not 'fit in' there.

One professional suggested that it would help parents with learning difficulties if they could attend antenatal classes throughout their pregnancy, rather than just at the later stages like other parents; this would give them more time and opportunity to absorb all

the information available. One learning difficulties service told us they ran a specific antenatal class, in conjunction with local midwives, for expectant parents with learning difficulties. These classes were seen as particularly valuable for parents who were frightened that their children might be removed from them.

Workers supporting parents with learning difficulties described how they had been raising awareness within generic services about the support needs of parents with learning difficulties prior to the birth of their child, through:

- The involvement of midwives and maternity service staff in the development of protocols and pathways (see Chapter 7)
- The development of a local 'maternity alliance' (involving all relevant professionals)
- The provision of information about the support available to parents with learning difficulties
- Training for midwives about the support needs of parents with learning difficulties.

Workers might also need to raise awareness about parents with learning difficulties, with: the supervisor of midwives at each hospital; the midwife responsible for child protection and the local supervising authority for midwives (Kirby, 2003).

Contact details for local supervising authorities for midwives are available at [http://www.nhscareers.nhs.uk//nhs-knowledge\\_base/data/566.html](http://www.nhscareers.nhs.uk//nhs-knowledge_base/data/566.html)

## The Role of the Midwife

Midwives' work is centred on the mother and baby, with everything being needs-related. They are involved with a woman from the time she knows she is pregnant until around 10 days after the birth. This, however, is flexible depending on individual need, and they can be involved until three months after the birth. Each NHS trust has a midwife responsible for child protection, and a supervisor of midwives. The supervisor of midwives would be a useful first contact for services wanting to improve what they offer for women with learning difficulties. If the mother has already had a child on the at-risk register, midwives have a duty to refer them to social services. If they identify that a baby is not reaching, or may not reach, its full potential, they have an obligation under The Children Act 1989 to act.

In two areas, staff from community learning difficulty services said they had specifically chosen to move into posts in maternity services in order to raise awareness there of parents with learning difficulties.

## Summary

### Identifying parents with learning difficulties

Early identification of (prospective) parents with learning difficulties by professionals in mainstream services is vital if parents' support needs are to be met from the outset. Ways of facilitating this include:

- Raising awareness of the existence and needs of parents with learning difficulties through leaflets, meetings, etc
- Developing tools to help staff identify whether an adult has a learning difficulty
- Developing joint protocols/care pathways.

### Pre-pregnancy and ante-natal advice and support

Essential ingredients of successful support to adults with learning difficulties, before and during pregnancy, are:

- The production of easy to understand information
- Providing support and time for parents to understand the choices available
- Early contact with all relevant services
- Awareness on the part of generic services of the needs of prospective parents with learning difficulties
- Close work with maternity services.



# Chapter 6 Providing effective support

***If it wasn't for them I wouldn't know what to do.***

(Parent with learning difficulties with a daughter with autism)

## Introduction

This chapter looks at the different ways in which professionals were providing positive support to parents with learning difficulties.

It begins by looking at the assessment process, and the tools used in this process. It then considers the various components of effective support provision, including: skills training and knowledge development; parenting groups; the sort of support parents want; the need for flexible support to meet families' changing needs; the provision of emotional (as well as practical) support to parents and the role of the extended family.

## 1. Assessing parents' support needs

Workers in services supporting parents with learning difficulties used a wide variety of strategies to assess parents' support needs although the *Parent Assessment Manual* (McGaw et al, 1998) was the most frequently used assessment tool.

***Sue McGaw's parenting pack is useful but lengthy. We often adapt it to the individual.***

(Psychologist)

Professionals involved in this study confirmed a key theme permeating the recent literature (Culley & Genders, 1999; Morris, 2003), namely that assessments should be holistic: they should include the wider social context of each family, and the impact on parenting of poor environmental circumstances, stress and social isolation (Feldman et al, 2002; McGaha, 2002; McGaw & Newman, 2005). They felt that:

***...assessment framework has a narrow view of the social context [whereas] parents speak of abuse, racism, stones thrown at their windows.***

(Community nurse)

Ideally, assessments should focus on both competency and safety, highlighting parents' skills and abilities as well as areas where help will be needed. They should be undertaken in the context of the support that is now available to parents (McGaw & Newman, 2005), rather than in the light of their previous history.

In one area, workers from services supporting adults with learning difficulties had negotiated changes in the arrangements for supervised contact (where parents have contact with their children but are monitored while doing so). These changes meant that parents could be supported in gaining skills, and could demonstrate that they were capable of learning how to meet their child's needs. This was more positive and helpful than making parents feel that they were simply being 'watched to see if they are doing it wrong'.

## Assessment tools

*Learning curves: The assessment of parents with a learning disability: a manual for practitioners* (Morgan & Goff, 2004) provides an insight into the increased vulnerability and stress experienced by parents with learning difficulties because of their disadvantaged social environments and backgrounds. It also provides strategies for appropriate assessment and stresses the importance of needs-led support and ongoing teaching for parents.

Another pack, based on the Department of Health's *Framework for the Assessment of Children in Need*, is specially designed for use by community nurses and includes a wide range of topics, such as preparing for the baby, hygiene and safety, play stimulation, child development and coping with stress (English, 2000).

Participants in the study also recommended psychological assessments and speech and language assessments, to ensure that the professionals involved with individual parents communicated with them appropriately and to:

**...ensure expectations are fair for parents with learning difficulties.**  
(Psychologist)

One speech and language therapist felt that using communication ages (ie 'he communicates at the level of a ten year old') was by far the most successful way of supporting staff inexperienced with people with learning difficulties to communicate appropriately with parents, even though such labelling could be seen as 'derogatory'.

Professionals stressed that additional time was needed during assessments to enable staff to develop an honest relationship with parents and gain a greater insight into the nature of their impairments and their individual support needs. The assessment should be undertaken in the parents' home or some other supportive environment where they would be more relaxed. Afterwards parents should be told, clearly and honestly, the outcome of the process.

## Community Based Assessment

Circles Network (see Box in Chapter 1) offers community based assessments that include short term direct support to assess how well parents learn, and to get a real feel for how they interact with their children. The assessor starts with a chat about what has worked and how they have learnt to be parents. Often the response is: 'No-one shows us.' 'No-one tells us we've done it wrong'. The assessor makes as many visits as needed to complete the assessment. Much of the direct work following the assessment is based on what the parents want to learn. The Circles worker works alongside the parents and models the behaviours and skills required, so that the parents can see the approach works before trying it. Options are given: what about trying it this way? The worker gives parents plenty of time to think about things, as they may need longer to process and understand what is being suggested. In Circles' experience, parents very quickly want to know what the issues are, and what they need to do to keep their children and how realistic this is. The worker is always honest in response, and tells them what the expectations and standards are. The assessor returns to check with the parents how well they feel they have coped with the support offered. The final report to the courts makes recommendations for any further support needed – this may be

an advocate, skill teaching around play and stimulation, non-literacy based materials, etc.

(For more information on child protection and court processes, see Chapter 8)

## 2. Skills training and knowledge development

Supporting parents needs to start from an early assessment of the skills and understanding they already have. The strategies used by professionals to help parents develop their parenting skills further include:

- Clear communication, and ensuring parents have understood what they have been 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
- Working with parents themselves to develop helpful resources.

### Helpful resources

Resources used to help parents develop relevant skills and knowledge included:

- *First steps to Parenthood* (Young & Strouthos, 1998)
- *You and your Baby* (Affleck & Baker, 2004)
- *The Parenting Skill Cards* (McGaw et al, 1999)
- *I want to be a good parent...* booklets (McGaw, 1995)
- Specific resources developed for the individuals concerned, through joint working with speech and language therapists or a health visitor (cf. Rose, 1994)
- Adapting portage materials (home-based teaching programme for pre-school children, involving parents. cf. McGaw, 1994)
- Use of a 'virtual' baby: a doll that imitates a baby, crying at regular intervals
- Use of visual aids particularly to explain birth and the pain involved.

## The Pregnancy Album

One midwife is developing with parents 'an album of the journey' through their pregnancy. The album (or video) includes materials appropriate to those parents, such as informative illustrations, video clips, and photos. It also records the pregnancy through photographs of the mother at different stages.

## Teaching parenting skills

Skills training needs to be carried out in the parents' home, using the actual equipment they will use with their baby. Parents involved in the study pointed out that when they went to an assessment centre, they lost contact with the professionals they had learned to trust. Being away from home, often for very long periods of time, also caused further distractions from focusing on learning how to parent. Such distractions included the risk of losing jobs, worrying about pets and the security of the family home, and lack of regular access to family and friends who could support them.

Attendance at parenting groups (see below) was also regarded as an important way of improving parents' social skills and confidence, so that they would eventually be able to take part more effectively in other meetings about their support needs, and to access mainstream groups aimed at supporting parenting skills:

***Support parents to have group support, such as parenting or social skills groups, where they can improve their social skills and learn about groups, before supporting them to attend local parents' groups such as Home-Start and toddler groups.***

(Community Nurse)

If parents are to attend mainstream groups, such as a local breast feeding group, they may need a professional to accompany them and they will probably need to have transport provided.

## 3. Parenting groups

Parenting groups have been developed in a number of locations around the UK. Two groups visited as part of the research were being run by the parents themselves and becoming independent from the service which had set them up. Another group was run by a mother with learning difficulties, employed by a parenting project, with help from her support worker.

Two services had set up 'drop-ins' for parents, particularly for parents who were not receiving direct support from services.

***I have set up a drop-in for parents with learning difficulties along with an advocate and portage worker to offer long-term support and a regular point of contact, to advise on a variety of issues. It also serves as a social function of enabling parents in similar situations to meet, offering mutual support and guard against social isolation and to promote child development. The drop-in has been running since Sept 2004 and numbers have slowly increased. Parents are now getting involved in running the group and are inviting speakers along once a month, eg police officer, playworker, dietician.***

(Community nurse)

Workers running parents' groups confirmed that they were a cost-effective method of supporting parents with learning difficulties, which improved their social networks, self-esteem and ability to challenge discriminatory views of themselves (Barlow, 1999; Booth, 2000; Kroese et al, 2002; McGaw et al, 2002). Ongoing group support allowed staff to remain vigilant regarding any potential child protection concerns, and gave parents access to informal discussions with professionals. Workers could also provide support to parents with learning difficulties who were not in direct contact with services, but who were in need of informal support of some kind.

A wide variety of professionals from different backgrounds were involved in the different parenting groups, including: community learning difficulties nurses, occupational therapists, child protection professionals, psychologists, social workers, portage workers and advocates. One group providing information to the survey was initiated by an advocacy organisation, while others were run in conjunction with Sure Start.

Those involved with parenting groups stressed that they should:

- Be held at a neutral venue not associated with children and families services
- Be held at a regular day and time
- Provide transport – one service provided an escorted mini-bus to reduce time spent by workers picking up and dropping off parents
- Have a structure and ground rules
- Enable parents to relax, feel safe in the group and 'have a laugh'
- Enable parents to share their experiences with other parents – for instance, parents of older children sharing advice about soft drinks which do not contain e numbers, or how to negotiate with children's schools, as they 'had been there and got the T shirt'
- Support parents of school-age children, as many services only support families until children start school
- Reduce isolation for parents: in one service two single mothers spent Christmas together after meeting at the group
- Empower parents to act as educators and consultants for services.

It was felt important that staff supporting groups should make it clear to colleagues in children and family services that groups were for support rather than child protection purposes.

Topics covered by parenting groups varied according to the ages of the children and the issues currently faced by parents. They included such subjects as healthy eating, singing, bullying, play and money – including every day issues such as 'being in a muddle with bills' or 'people trying to make them change the electricity board.'

Groups were also:

***...go[ing] on outings to help parents function as a family.***

***...supporting parents to access community facilities.***

Staff involved in groups used a variety of strategies to convey information, help parents develop skills and 'tackle issues the parents are facing by facilitating effective communication' through confidence-building and role-playing difficult situations.

In addition to role-play, both parents and staff were encouraging all parents to share their experiences and inviting experts in to talk to them. A number of groups were also following adapted mainstream parenting programmes, including the Webster Stratton Positive Parenting Programme (see [www.incredibleyears.com](http://www.incredibleyears.com)), and *Family wise* pack ([www.oneplusone.org.uk](http://www.oneplusone.org.uk)).

The Webster Stratton Parenting course was condensed by one community service for parents with learning difficulties, into an eight-page booklet with an accompanying tape. The 12-week course was run for six parents and facilitated by two workers, who also adapted exercises to reduce the need for literacy skills (for instance, using cutting and sticking exercises). This course was followed up by 'homework', in the parents' homes, facilitated by support workers from the service.

In a number of parents' groups the workers involved also supported parents in developing the skills they needed to participate in other meetings.

***Part of the parenting course looks at the role of professionals and how parents can work with them to learn more effectively.***  
(Social worker working with adults with learning difficulties)

Parents were encouraged to develop and follow ground rules, devise agendas and gradually take more responsibility for the running of the groups.

### **Elfrida Society Parenting Group**

The Elfrida Society in Islington actively supports parents with learning difficulties by providing a coffee morning for them, facilitated by a parent with learning difficulties and her support worker. As Mahmuda Murshed (2005) writes in the journal *Disability, Pregnancy and Parenthood International*, the group provides peer support for parents with learning difficulties who feel vulnerable and alone. The parents' views about how the coffee mornings should run were sought, via a questionnaire, at the outset. The mornings have a structure and ground rules and the parents invite visitors, such as speech therapists and health visitors, to talk to them. The parents share ideas and have talked about issues such as bullying, smacking children and their relationships.

A psychologist comes to the group each week to help the parents think about issues. Murshed says that she learns more each week about the best ways to run the group and support the parents. One issue she is thinking about is how to support parents who have not got their children with them. At the moment, these parents come along to the main group, along with those who still have their children.

At the time of writing the group was applying for funding to take the children on trips in the summer. This would help the parents gain confidence in using a range of community venues and give them a chance to have fun with their children.

The service also supports parents on an individual basis and engages with local professionals by organising meetings and encouraging agencies supporting parents with learning difficulties to communicate more effectively with them and each other.

For further information contact:

**Mahmuda Murshed or Susan Moore**

**Tel: 020 7354 6349**

**Email: [parenting@elfrida.com](mailto:parenting@elfrida.com)**

Involvement in parents' groups had empowered parents with learning difficulties in a variety of ways. Different groups and individual parents had trained professionals, become consultation forums, been involved in the development of the *CHANGE You and Your Baby* book (Affleck & Baker, 2004) and developed leaflets for other parents about the services available locally.

A difficult issue for some parenting groups was how to provide support for parents whose children had been adopted (Murshed, 2005). In a number of the services visited, such as the Elfrida Society, parents who no longer had their children were attending groups alongside parents whose children still lived with them. Parents and workers alike recognised that this was not ideal:

***It is painful but it's their support network.***

(Psychologist)

#### **4. What sort of support do parents want?**

Parents in the project's advisory group wanted their supporters to:

***...take feedback... listen... pay attention [and] ...do what you ask.***

In particular, they were keen that they should:

***...not judge us [and should] have confidence in us and trust we can do it.***

Parents with learning difficulties in Berkshire summarised the areas where they need help as follows:

- Getting the children to do what they need to
- Helping with homework
- Trying to explain things to children
- Managing children's behaviour
- Being patient
- Keeping children safe
- Helping their children to make friends

- Going to parents' evenings
- Understanding what professionals say.

(West Berkshire Mencap, 2004)

In addition, the parents said they needed help with transport, paperwork, understanding big words, managing finances and practical tasks around the home, as well as in relation to issues of harassment, bullying and protecting themselves.

Additional examples of the kind of support that parents have found helpful can be found in Chapter 1, Section 4 and Chapter 4, Section 2.

## **What professionals need to provide**

Professionals involved in our study were clear that positive, competency promoting support (Richardson, 2001) should be provided, rather than the assumption being made that children were automatically at risk (Llewellyn et al, 1999; Olsen & Clarke, 2003; Sheerin, 1998; Tymchuk et al, 1990). The support should be 'competency building, child safety focused rather than risk focused support' and should address the parents' wider social context. Support needed to be provided from a 'family perspective', and to respect parents. It should enable them to show whether they could be 'good enough' parents when provided with the right long-term flexible support, given that:

***The main predictor of competent parenting is an adequate structure of professional and informal support.***

(McGaw & Newman 2005, p 24)

Staff described the support provided thus:

***...help[ing] the parent to learn how to parent.***

(Support worker)

***All the work is through the parents but reflects the needs of the children.***

(Community nurse)

***You need someone with no prejudices, who doesn't think they know it all, won't take over but will enable people.***

(Community nurse)

***It's about letting them realise that you are listening to them and taking them seriously... not bossing or judging, just being on their side.***

(Support worker)

## Stockport Community Team for Parents with Learning Disabilities

We spoke with a community support worker in Stockport who sees her job as supporting parents with the tasks of everyday living, such as shopping, budgeting, cooking nutritious meals and helping with mail. She describes herself as a friendly face and non-judgemental in her approach, considering that the best way to gain the parents' trust and build a relationship with them that will in turn enable their children to have the best upbringing.

She is aware that the parents have met much criticism in the past from other professionals. She makes sure that she praises their achievements, so that they can gain confidence to continue developing their parenting skills.

Boundaries around child protection are clear; she has reported actions that have concerned her in the past. The child protection training she has received has been helpful in knowing the boundaries and explaining to the parent why she had to act as she did.

The amount of support offered to parents varies according to their needs, and can be reduced or increased, according to how these needs change. There are regular three monthly multi-service meetings to look at the progress of individual families.

The support workers regularly speak to other professionals about parents' achievements or about concerns. This is an important part of adopting a consistent approach so that everyone is using 'the same hymn sheet.'

The Stockport service also provides a high level of support when a parent is referred to them. A social worker or community nurse supports parents with issues such as debt, poor housing, intimidation and child protection proceedings. When the crisis which has brought parents to the attention of services has passed, the support worker or external agency provides ongoing support.

The service, also provides an adapted Webster Stratton Parenting Course ([www.incredibleyears.com](http://www.incredibleyears.com)) and supports a parents' group which is becoming self determining. The interagency pathway for use with new and prospective parents with learning difficulties (see Appendix 3) was devised by a multidisciplinary steering group involving the community learning disability team, children's social work team and teenage pregnancy coordinator, midwifery service, health visitors, education and the voluntary/community sector, including the local advocacy service.

For more information contact:

**Denise Monks**

**Tel: 0161 4914376**

**Fax: 0161 4914148**

**Email: [denise.monks@stockport.gov.uk](mailto:denise.monks@stockport.gov.uk)**

In order to provide positive support, and learn from the parents as well as support them (Ray et al, 1994; Richardson, 2001), staff need to:

- Listen to, and emotionally support, parents
- Work at developing a relationship with parents who might be reluctant or afraid to engage with services
- Praise parents' achievements and support the development of self esteem
- Be creative and 'think outside the box' to find and develop strategies that support individual parents in their role
- Break down tasks into small steps
- Communicate clearly
- Have a non-judgemental attitude
- Refer the child/ren back to the parent, so that the parent remains in control
- Be honest and clear about what is expected of the parents
- Work in a consistent way with other staff involved with the family so that parents are not confused by differing advice from different people
- Consult with, and follow advice from, appropriate experts (eg midwife, health visitor)
- Have knowledge of child development
- Pay attention to detail – such as the amounts of milk given to a baby or the amount of medication given to a child when they are ill
- Understand the boundaries of their role, ie to support parents rather than do tasks for them
- Remain vigilant about child protection concerns.

### **An Occupational Therapist's Role**

One occupational therapist involved in supporting parents with learning difficulties described her role as 'skills facilitation'. She sat in on visits with the midwife, taking notes so that she could repeat what the midwife said, using exactly the same words. She then returned to practise the skills with the parent. When the skills had been mastered, she made a booklet showing the parent undertaking the task (using photos of the parent) to act as a reminder. This level of support and involvement reassured the midwife that the parent was being supported to develop the appropriate skills.

When more than one worker is supporting a family, it is clearly important that support should be provided to the parents in a consistent manner. The following strategies had been found to be helpful here:

- Meetings of all the workers involved to discuss current aims and strategies
- Joint training – in one instance this included the mother with learning difficulties, so that she knew the behaviour strategies to be employed with her children
- Continual phone contact between workers
- Use of a communication book kept by the family so that everyone can keep track of:
  - Who has been to the house
  - What has been done
  - Any issues or successes.

One professional commented that this consistency between workers needed to extend to seemingly minor details, such as all workers entering the house and asking to be allowed to take their coat off, before the parents talked to them about what had been going on.

Parents and workers differed in their opinions about the best age and level of experience required of support workers. While young people with appropriate attitudes were considered easier to employ and train, some parents said they would not respect a supporter who was not a parent themselves. Older workers with children, however, could be set in their ways and take over the parenting role. Such differences of opinion highlight the importance of selecting the right worker for each family.

## **5. Flexible support to meet families' changing needs**

Clearly, the support provided to parents with learning difficulties needs to be tailored to the family's needs at any one time. Our study found that day to day support was generally provided early in the morning and again in the early evening to help with children's routines, such as getting ready for school, doing homework and getting ready for bed. During the day some children attend a childminder or nursery, which gave some support to the parent, and also helped to ensure that the children were socialising and being stimulated appropriately. Day care is seen as one way of preventing the possibility of cognitive delay from under-stimulation in the children of parents with learning difficulties (Appleton et al, 1975; McGaw, 1994).

Parents in this study were also supported in attending appointments and dealing with household issues such as bills or budgeting, understanding letters or contacting schools. They were also helped to develop other skills they needed, such as basic cookery skills and an understanding of healthy eating.

Professionals felt that there were three transition stages in children's development where parents would need additional support. These were:

- When the baby became a toddler
- When the child started asserting its authority at seven or eight years of age
- When the child became an adolescent.

At these times, in particular, staff recognised that it was important that they were thinking 'six months' ahead' and 'about upcoming issues', as well as remaining flexible and available to support parents during any unexpected crisis.

### **Parenting Support Service, North Tyneside**

This service is provided by a small team which is part of a local Community Learning Disabilities Team. The team is made up of community nurses and support workers who specifically support parents. While some of the nurses have cases other than parents, those who exclusively work with parents have 6 or 7 families on their books at any one time, as intensive support is provided. A nurse co-works with support worker.

The team supports around 25 families in all. The children's ages range from babies to age 15, with most aged 5 – 13. The team tends to be involved with families on a long term basis and the support provided to the parents reflects the needs of the child. They work with other services as appropriate – school homework group, health visitor, etc. Parents can attend a support group which provides peer support, and helps parents develop skills through discussions, invited speakers and using adapted parenting courses.

For further details contact:

**Clare Arnold**  
**Parenting Support Service**  
**Community Learning Disabilities Team**  
**Camden House, Camden Street**  
**North Shields, Tyne and Wear**  
**Tel: 0191 200 1077**

Staff were aware that parents might need more, and different, support when their children were older and, in many cases, starting to 'intellectually outstrip' their parents, such as around moral dilemmas and providing appropriate stimulation (Woodhouse et al, 2001).

Strategies used to support parents with older children included:

- Liaising with the child's school
- Use of homework clubs
- Providing a worker in the early evening, who could help with homework
- Role-modelling activities, such as playing a board game
- Having a person-centred plan for each member of the family
- Providing a male support worker in families where there were older boys
- Supporting parents in accessing relevant local amenities
- Involving a reliable, independent adult to provide advice and support to the children.

## 6. Emotional support

The provision of positive support to parents, who are often socially isolated (Llewellyn & McConnell, 2002; Feldman et al, 2002), included workers spending time to develop relationships with parents and to support them emotionally, by:

- Listening to them
- Praising their achievements
- Explaining their situation to them, and being honest with them about it
- Being available to parents when they needed support
- Supporting parents during their interaction with other professionals/agencies, including supporting parents in accessing mainstream services.

***My own work is more in the area of emotional support for parents, acting as a safety valve, especially when the pressures of being evaluated are very great. Also consistently valuing, explaining, working out what may be happening. Have had to stretch my role to sort out misunderstandings quite often – especially... when people struggle with very negative attitudes.***

(Advocate)

Workers stressed that providing emotional support to parents was vital, in order that they engaged with services, so that they could then show if they could be 'good enough' parents:

***Self esteem issues vital to work on, so that parents can feel more confident in functional tasks.***

(Community nurse)

Staff were aware of parents' vulnerability and low self-esteem. They recognised the stress caused by the 'judgement' and 'continual scrutiny' of the child protection process and the 'fear that their past history will be used against them' and that their children would be taken away. Advocates and other support workers were acting as a bridge, or intermediary, with other services, in order to ensure that they treated parents with respect and communicated appropriately with them.

It could take a lot of hard work over a period of months to build a relationship with a parent who was 'afraid of services'. In one service, however, developing a relationship with parents was facilitated by the fact that their support was provided via a voluntary (rather than compulsory, child protection determined) relationship. Parents were empowered by the fact that they 'could tell workers to go away'.

The provision of emotional support is of particular importance if children are removed from their parents. Fiona, whose story was told in Chapter 4, is currently bringing up her youngest two children with support from services, but she cried throughout her interview for her other four children who had previously been adopted. She was determined that these children would come back and find her when they were older.

Parents involved in the advisory group for this project similarly discussed the ongoing heartbreak felt from having their children removed over 20 years before.

Other parents involved in this study said they felt 'cut off' from support from services once their child had been adopted. Some workers recognised that parents who had had children adopted continued to see themselves as parents, and that they should be offered ongoing emotional support and help to restart their lives.

***More work with parents who have lost children, including long-term therapy groups for such parents and others who have had very painful experiences.***

(Clinical psychologist)

Support offered by workers in this area included:

- Helping parents to write letters to their children, or to make life-books for them, including photos and the reasons why they couldn't look after them
- Helping parents to understand the reasons why they could not be an active parent
- Supporting parents to work through their feelings of grief at the 'loss' of their child/ren
- Helping parents to get on the adoption register (so that children could find them in years to come)
- Advice about finding new partners and relationships
- If appropriate, supporting parents to use the letterbox scheme (for contact with their child who had been adopted)
- Supporting parents when there were difficulties over contact with a child who had been adopted.

One couple involved in the project advisory group had spent months eagerly anticipating their annual letter and photograph of their daughter. When they finally received the photograph, later than the expected date, the picture of their daughter was not clear. Such disappointment added to their continuing feelings of frustration, mistreatment and loss.

## **7. The role of the extended family**

The recent national survey of adults with learning difficulties in England (Emerson et al, 2005) found that 58% of the parents with learning difficulties, who still had their children living with them, were themselves living either with their own parents (15%) or other relatives (43%). Clearly, the extended family can provide vital support to parents with learning difficulties and their children. Informal support may also lead to increased social networks for parents and their children (Llewellyn & McConnell, 2002).

Support from the extended family can work well. One positive example encountered in our study was of a father's sister providing 'shared care' for his children. The arrangement was monitored by child protection procedures, without the case going to court. Similarly Bethany (see Chapter 4, Section 2), the mother of a four year old disabled daughter, was grateful when her community nurse helped her move closer to her mother. In the service we visited which was supporting Bangladeshi parents with learning difficulties, the extended family often played a substantial role in the upbringing of the child (see Box).

## **'Expected to be a parent': the perspective of a service supporting Bangladeshi parents**

The following themes emerged from the work of one service we visited that supported parents with learning difficulties from the Bangladeshi community:

- An expectation of marriage and parenting for people with learning difficulties
- Some concerns about the disabled individual's ability to consent to marriage and sex
- Parenting of the child by the non-disabled parent or the child's grandparents with little involvement of the parent with learning difficulties.

Within this community it was accepted that people with learning difficulties would want companionship and intimacy. An arranged marriage for people with learning difficulties was 'expected.' The parents of the young person with learning difficulties arranged the marriage, usually with a non-disabled relative, who would know about their marriage partner's impairments. The parents, had little trust in services supporting their grown up child and wanted to ensure that they had a new family to care for them, once they had passed away.

The workers we spoke to (one white and one from the Bangladeshi community) were aware of concerns amongst some professionals regarding the adult with learning difficulties' ability to consent to marriage and sex. They recognised that Bangladeshi parents with learning difficulties often had more severe impairments than the white parents with learning difficulties they supported. They noted that there was also a debate amongst the Bangladeshi community regarding the marriages: some members of the community expected all young people to marry while others felt if the adult could not understand what they were entering into, they should not be married.

This one example is an indication of the pressing need for more research or development work to be carried out into the support needs of parents with learning difficulties from different minority ethnic communities. (See Chapter 9, Recommendations, p96).

Some professionals mentioned instances where interested families had not been informed when major decisions were made about children, including cases of abortion and adoption.

### ***Grandparents are not seen as part of the child's future. Contact is lost with them and other family members.***

(Community nurse)

Elsewhere, the involvement of extended families was often inhibited by the lack of local family members.

Where parents with learning difficulties want the extended family to be involved it is important that any support provided remains:

***...focused on the parent and their preferences while respecting family dynamics.***

(Advocate)

The involvement of the wider family needs to remain supportive or 'protective' (Barlow, 1999) with the parent in control. Some workers in our study reported that families could sometimes 'take over' or undermine professionals' relationship with the parents.

***Extended family usually rescue and take charge and look after the baby.***

(Social worker working with adults with learning difficulties)

***Extended family often discourage parents from engaging with services and provide conflicting advice.***

(Social worker working with adults with learning difficulties)

Where this happened, parents with learning difficulties could be left feeling that their own parents or siblings were taking their children away from them.

Some families were not considered suitable support providers by the professionals involved, and were described as 'demanding in their own right', 'volatile' and 'obstructive'. In a number of cases, family backgrounds were considered 'dangerous' or 'abusive', providing environments from which the parents with learning difficulties, as vulnerable adults, should themselves be protected. Often workers were struggling to change parenting behaviour that had been passed down through the generations.

## **Strategies for involving extended families**

Professionals were attempting a difficult balancing act, in which parents' views and needs were kept central, while involving their extended family when appropriate, and understanding the issues from their perspective too. Strategies used to support the involvement of extended families included:

- Spending the time needed to develop the trust of extended families
- Observing and listening carefully, to understand the particular roles of individual family members
- Explaining to family members the support provided to parents and the child protection system, ensuring particularly that family members understood that within judicial proceedings normal confidentiality rules do not apply
- Keeping families informed of developments (with the consent of the parents) by having meetings with the parents and the family together, where appropriate
- Clearly outlining professionals' and advocates' roles, and their boundaries
- Remaining vigilant about the impact of the level of involvement of extended family members so that family relationships do not deteriorate
- Not getting involved in family feuds.

One psychologist described:

***...use of systematic family therapy approach and family group conferences to mobilise family support.***

*Family group conferences: Principles and practice guidelines* (Lawrence & Wiffin, 2002) provides more information about family group conferences.

## **Kinship Care**

Morris's literature review on supporting disabled parents highlights the fact that 'kinship care' – ie where members of the (extended) family care for another members' children, often because they are unable to do so themselves – is associated with greater stability for the children concerned and better continuity in terms of family and cultural issues than foster care. But there is also evidence that 'kinship carers' are likely to experience greater economic difficulties and poorer accommodation than other, non-kin, foster carers (Morris, 2006).

## **Summary**

### **Assessing parents' support needs**

- Assessments should be multi-professional/agency and adjusted to the parents' level of competency, rather than to their IQ
- Assessment of the parents' level of comprehension is vital, so that professionals know how best to communicate with them
- Time is needed to undertake assessments properly and explain them to parents.

### **Skills training and knowledge development**

- Early assessment of competencies is important
- Easy to understand information or adapted materials are needed
- Time is needed to work at the parents' pace and to liaise with others
- It is important to teach in a person-centred way and to break down concepts into small parts which can be easily understood
- It is important to work closely with midwives/health visitors/appropriate specialists.

## Parenting groups

Parenting groups are an effective way of helping parents, particularly since they:

- Can use mainstream parenting materials, adapted for parents with learning difficulties
- Work with issues of importance to parents at that time, eg harassment, bullying, healthy food
- Provide peer support, recognition of achievements and sharing of experiences
- Reduce isolation
- Provide support during school holidays
- Enable parents to access community facilities
- Enable parents to exercise control of the group (which is empowering)
- Make possible ongoing contact with workers for informal advice and support
- Build up parents' confidence by giving them the opportunity to practise skills eg participating in meetings.

## What sort of support do parents want?

- Parents value staff who are there when they need them
- Staff can help empower parents by praising and acknowledging the skills they already have, not judging them but supporting them in creative ways
- Parents value honesty and clarity
- Parents need to understand different workers' roles and boundaries
- Parents need support to engage with other professionals and agencies, including generic, mainstream services
- Parents need consistency (facilitated by ongoing communication between workers)
- The type of support provided needs to be flexible and respond to the family's needs at that time; different, maybe more, support will be needed as the children grow older
- Support needs to be ongoing, even if children are adopted.

## Involving the extended family

- The extended family should be involved, when appropriate, but on parents' terms
- Workers need to have clear boundaries and not get involved in family feuds
- Clarity is needed in discussions with extended family members
- It is important to ensure all family members understand the child protection process
- Family group conferences and systematic family therapy may be helpful.



# Chapter 7 Engaging with other services, advocacy and multi-agency support

**[You try to] build parents' confidence to enable them to slowly begin to liaise with agencies themselves with your support, only pulling back when the parent feels confident in doing so.**

(Advocate)

## Introduction

This chapter looks at how professionals can support parents to engage productively with local services, the role of advocates and at effective ways of delivering multi-agency support.

### 1. Helping parents engage with other services

Professionals involved in our study were encouraging parents to engage with other agencies and were also working with mainstream services to make them more accepting of parents with learning difficulties, and more responsive to their needs. Staff outlined the following strategies which had been helpful in supporting parents' engagement with local services:

- Ensuring that a positive, competency promoting, assessment was carried out; this meant other agencies could understand the parents and their skills and abilities, as well as their support needs, and could respond supportively
- Making it clear to other services how parents wanted to be addressed
- Helping parents remember who different workers were by providing photographs of them
- Helping parents understand each worker's role and being clear about what was happening
- Reaching an agreement between professionals on expectations
- Helping parents understand what was expected of them by simplifying information and presenting it clearly
- Attending meetings with parents.

Individual professionals often took on the role of keyworker to support parents' involvement with services provided on a multi-agency basis. (This is discussed further in Section 3 below).

Whenever possible, workers were also encouraging parents to access mainstream services, such as Home-Start or Sure Start, which support the development of parenting skills. One specialist community learning difficulties team was:

***...trying to become a referral agency for local services like Sure Start and the local vegetable box scheme [for families on a low income].***

(Community nurse)

McGaw (1994) highlighted the fact that parents with learning difficulties may be rejected in, or 'stick out like a sore thumb' at, mainstream groups such as antenatal classes, NCT (Natural Childbirth Trust) and Home-Start. While some parents were positive about their experiences with Home-Start (see Box) other parents did not like groups with 'outsiders' because they did not feel comfortable.

To address this issue support workers were:

- Providing awareness raising/communication training for mainstream services
- Running groups in conjunction with Home-Start (see Box), Sure Start etc
- Supporting parents to attend meetings/groups/toy library
- Mapping all the local services for parents and children and producing an accessible booklet about them to encourage their involvement.

## **Home-Start**

Home-Start runs a national network of home visiting volunteers and 330 local schemes providing emotional support and practical help to families with young children who are struggling to cope for a variety of reasons, including a parent's disability. The volunteers are themselves parents, trained and matched to support individual families. Each scheme is autonomous and self funded.

The volunteers have training that covers communication, stress factors, confidentiality and child protection amongst other topics. Referrals come from a variety of professionals including health visitors. Sometimes parents self refer.

The role of the volunteer parents – who are asked to work around four hours a week – is to provide the support a family needs. This may be support for hospital visits, reading letters or a couple of hours' respite. For many parents the important thing is that these people are volunteers who are themselves parents, not more professionals. The voluntary status, and the fact that they are parents, seems to make a difference to the way the service is received.

The volunteers are monitored and evaluated by the scheme coordinator, who also provides supervision. The supported parents are involved in every step of monitoring. As a result the parents feel more in control of their family.

One particular story was told of a couple with learning difficulties, both of whom were drug users. They had a toddler of 18 months. The mother would often leave for days, and leave the father with the boy. The mother eventually met someone else and left. A volunteer worked with the father and child, helped with feeding, potty training and especially stimulation. The father also gave up using drugs at this stage. The mother later reappeared and wanted the child back, but the father wanted to keep him. Home-Start were asked for a support letter to show he would be the better parent. He got custody, is doing well and now uses a family centre. The volunteer had been in a position to

observe the father's care and interactions away from professionals and so could confirm that what he was doing was 'good enough'.

Volunteers can offer different parenting skills, asking the parents what they have tried, then say 'What about trying this way?' They can work on boundary setting and child development, saying 'I remember when this happened with mine...'

***Home-Start doesn't mean you're failing as a parent, we're just there to help you through a difficult time.***

(Home-Start manager)

**Website: [www.home-start.org.uk](http://www.home-start.org.uk)**

## 2. The role of advocates

***Our aim is to give people with learning difficulties back their rights, choices and power to be in control of their own lives.***

(Advocate)

In some areas specialised advocacy services support parents with learning difficulties and their families, both generally and specifically in relation to child protection and court proceedings. Advocates in these services are likely to be paid professionals, employed by a voluntary agency (eg Mencap). In other areas, advocates may be unpaid volunteers, operating in a similar way to other 'citizen advocates' supporting or speaking up on behalf of parents.

Parents in our study valued the support provided by advocates, saying that they:

***...help out with writing letters***

***...argue their points across***

and were

***...good at problem solving and keeping social services on their toes.***

For their part, advocates saw their role as:

***...enlightening professionals about upholding people's rights, explaining people's access needs and their right to have these upheld, and working in a person-centred way, which many professional are not wholly taking on board. Our difference from other services gives rise to challenges and opportunities for reflection.***

A number of the advocates who responded to the survey specifically cited Tim and Wendy Booth's work regarding advocacy support for parents with learning difficulties (eg Booth & Booth, 1998;1999) to illustrate their role.

In accordance with the general principles of advocacy and guidelines for the involvement of advocates in child protection (Lindley & Richards, 2002), advocates supporting parents with learning difficulties felt they should:

- Support parents at their invitation and act on the parents' wishes
- Enable the parents' voice to be heard and not give their own opinions
- Empower parents, where possible, to speak up for themselves
- Support parents to make their own informed choices
- Ensure that, wherever possible, decisions were made with the consent of parents
- Be independent of the services supporting the parent
- Explain their role clearly to others
- Have a person-centred, non-judgemental style
- Be honest
- Be able to negotiate with all parties
- Be able to challenge services when appropriate
- Where possible, have an understanding of both children and family services and those supporting adults with learning difficulties.

## The Role of Advocate

One advocate involved in the study said that her job was to walk alongside the parents and do what they needed at that moment – eg to be a taxi driver, translate what is happening in court, put the kettle on. The role and relationship evolved with each person as they all became more comfortable with each other. The principles of work were to be there, be absolutely honest, be approachable, do what you said you would do, be tuned into them as people and really get to know them. She tells them at the beginning:

***This is an equal partnership. If I annoy you, tell me. If you annoy me, I'll tell you. I have no magic wand.***

(Advocate)

Some of the strategies used by advocates to empower parents included:

- Organising parents' groups and meetings between parents
- Getting parents to write a report or typing it for them on a laptop, so that they also had a report to hand out at meetings
- Ensuring parents were prepared for meetings through preparatory meetings to look at reports
- Asking for reports to be made accessible – or translating them into accessible language themselves

- Accompanying parents to meetings and ensuring meetings were run in such a way that parents could participate
- Supporting parents to take part in meetings or speaking for them, if required.

(For more information on the role of advocates in relation to child protection and court proceedings see Chapter 8.)

### **Training for Advocates Working with Parents with Learning Difficulties**

'Parental Rights and Learning Disability' is a course for advocates providing a detailed insight into the legal duties of statutory services, the *Framework for the Assessment of Children in Need* (DH, 2000), an introduction to court proceedings and the advocates' role.

For more information contact Advocacy Resource Exchange (ARX) (Previously CAIT)

**Tel: 020 8880 4545**

**Email: [arx@advocacyresource.net](mailto:arx@advocacyresource.net)**

**Website: [www.advocacyresource.net](http://www.advocacyresource.net)**

### **Advocacy roles played by other professionals**

Although advocates should ideally be independent of services supporting parents with learning difficulties, particularly during child protection proceedings, some kind of advocacy support role was adopted by many other workers, to ensure that 'parents have a voice in meetings'. As a professional in one area observed:

***Sure Start staff have been good at acting in an advocacy role.***

(Community nurse)

However, the provision of advocacy support by workers from services supporting parents with learning difficulties could conflict with their role in parents' assessments and in child protection proceedings. Professionals were aware that they could easily become 'compromised ethically' and that their long-term work with the family could be jeopardised:

***We sometimes get to a point where we can't be an advocate and a community nurse.***

(Community nurse)

In such cases, the role of the advocate was even more important. Advocates' ability to support parents with learning difficulties was, however, inhibited by a lack of awareness of the potential of their role on the part of other workers and a shortage of advocates generally.

### 3. Multi-agency working

Well organised multi-agency working, as recommended by the Children Act (2004), can help parents with learning difficulties to be 'good enough' parents, particularly when there are a large number of agencies involved in supporting them (Booth, 2003; English, 2000). Collaboration between children and family services and adult services is also key to appropriate and positive support (McBrien & Power, 2002), as are close working relationships between health and social services staff. *The Same as You?*, the review of services for people with learning disabilities in Scotland cites the example of Grampian Primary Care Trust which employs a specialist health visitor to support parents with learning difficulties. The project involved clinical psychologists, social workers and primary care staff working together (Scottish Executive, 2000).

#### Multi-agency working

In one area where parents are well supported, an advocate told us that she did not work alone: all the agencies worked together, as they knew they all wanted the same thing. Good communication was crucial, along with understanding and respecting each other's roles, and being aware of boundaries and limitations.

Coordinating support can be extremely complex, however. Woodhouse et al (2001) report 23 distinct teams of professionals involved with families referred to their clinical psychology department. The number of professionals involved in providing support to parents in our study was similarly wide ranging (see Table 2, Appendix 2).

The benefits of well organised multi-agency working are clear: as one professional commented:

***...uniting people in the desire to operate in positive ways where all share the desire to support the parent, it can become a supportive network, [workers] understand the stresses of many people being involved and work to minimise the stress to parents.***

Good multi-agency working means:

***...that parents know what is happening. All agencies are saying the same things. We learn from each other. Parents are clearer about what is expected from them. Agencies also have better understanding of each other's way of working and areas of responsibility.***

(Speech therapist)

Workers in services supporting parents with learning difficulties in our study were trying to ensure effective communication between services to support consistent multi-agency working, by:

- Ensuring that a contact person from the team specifically supporting parents with learning difficulties was available to provide advice and information to colleagues when needed

- Providing other agencies with approaches and tools to support parents' skill development
- Raising awareness of parenting issues by establishing or attending relevant forums
- Encouraging other professionals to understand that many of the issues these parents faced were the same as those faced by other families, particularly families from other vulnerable groups
- Taking on the role of keyworker, being the main worker to liaise with the parents and report to the various services involved with them.

***I think the parents see us as the key people, working with them and supporting them.***

(Social worker working with adults with learning difficulties)

## **Supporting Parents with Learning Difficulties in South Norfolk**

In South Norfolk a health coordinator for people with learning difficulties has brought together professionals from health, education, social services and primary care to coordinate the delivery of services to parents with learning difficulties in the area. Provision includes a fathers' group and a parenting course which is highly valued, as it is the parents who guide what is taught.

For more information contact:

**Bridgitte Shad**

**7 Norfolk PCT**

**The Courtyard, Ketteringham Hall**

**Ketteringham, NR18 9RS**

**Tel: 01603 813862**

**Email: [Bridgitte.shad@norwich-pct.nhs.uk](mailto:Bridgitte.shad@norwich-pct.nhs.uk)**

Developing effective shared working meant:

- Professionals trusting each other, being upfront and honest with all concerned, particularly when there were concerns that conditions were unsafe for children
- Regular face to face meetings and regular case reviews
- Ongoing telephone contact
- Gaining parents' consent for the sharing of information: one area had developed a specific consent process, in conjunction with speech and language services, so that workers could speak to colleagues in other services about parents' needs
- Being clear about roles and boundaries
- Undertaking joint training
- Valuing everyone's experience

- Recognising the support available from generic, mainstream services supporting parents.

There are inevitably barriers to collaborative working. One worker from Home-Start, for example, commented that it was easy for their service to be 'left out of the professional loop', even though they were successfully supporting parents who were very negative about other professionals. Other workers were concerned that strategies to support parents with learning difficulties should be included in other mainstream planning initiatives.

Local frameworks for appropriate services, joint protocols and care pathways have been developed in a number of areas to facilitate the different agencies' contributions to supporting parents with learning difficulties (cf. Morris, 2003). The involvement of child and family services was considered very important in the development of a protocol in one area, while in another the protocol was developed expressly because:

***Child protection wanted to be able to refer earlier, and commissioned someone to write and lead a protocol.***

(Social worker working with adults with learning difficulties)

Elsewhere, another area had set out:

***To develop and implement a joint working protocol that ensures a countywide, consistent and quality approach to assessing, planning and implementing appropriate support.***

(Overton et al, 2004, p5)

They had set up a time-limited, and focused, working group to develop a joint working protocol specific to learning disability, building on the existing generic draft protocol. The core elements of the protocol included:

- Eligibility and referral
- Roles, responsibilities and accountability
- Care pathways (joint assessments etc)
- Communications protocol
- Joint training and development.

(For examples of a care pathway developed in Stockport, see Appendix 3).

There are a number of ways that appropriate multi-agency support can be provided to parents with learning difficulties. West Berkshire Mencap (2004) suggest the following possible patterns of support:

- **A generic network of support**

Specialist services are available to provide assessment, specific interventions and advice, while generic services, families and friends provide ongoing support. This model is inclusive, and reduces the stigma for parents of involvement with learning difficulty services but requires attention to ensuring that the parents' circle of support is strong enough. A lead agency/supporter is required to coordinate support.

- **A virtual team of specialist support**

Pro-active support is provided by specialist workers, from various agencies, that operate together as a virtual team. A lead agency mobilises support for the parent as and when required and refers parents to specialist teams for advice and services.

- **A specialist learning disability parenting service**

A specifically designed service for parents with learning difficulties to which parents are referred by other services, and which provides advice and support to other services. Such services provide ongoing, flexible support to parents.

## **Special Parenting Service, Cornwall**

This is probably the best known, and longest running, specialist service in the UK, offering support to families where one or both parents have a learning difficulty. It provides home based services, assessment, teaching programmes, parenting groups and advocacy for parents. The service is funded by the Cornwall Partnership Trust to provide a comprehensive parenting assessment utilising the *Parent Assessment Manual* (McGaw et al, 1998) which assesses parents' knowledge, skills and practice across 34 parenting domains.

The assessment focuses on both the needs of the child as well as the parent and provides a risk assessment and priority ratings in terms of a family's need for support. In addition, a family history, psychometric testing and any other needs of the family may be assessed (eg mental health, parents' relationship, child development).

Intervention services and teaching programmes are provided (having been funded by Sure Starts across Cornwall), targeting the medium to higher priority ratings and skills identified by the *Parent Assessment Manual*. Under the Sure Start initiative these programmes have had a major focus on family preservation and child development.

A partnership with the local college (Truro College) was developed in 2000. The 'Parents Opening Doors' course was designed to provide training to around 20 parents with learning disabilities on literacy, numeracy, IT skills, parenting, healthy living (including cooking, diet and exercise) and social skills development. Transportation and childcare have been funded for the course, which has proved highly successful.

Multidisciplinary specialist training for professionals and members of the judiciary (for example, in using the *Parent Assessment Manual*) is provided across the UK. Dr Sue McGaw, consultant clinical psychologist and head of the service is well known nationally and internationally for her clinical work, research, development of resources and publications in the field, in particular, for the *Parent Assessment Manual* (McGaw et al, 1998) and *What Works for Parents With Learning Disabilities?* (McGaw & Newman, 2005).

**Website: [www.cornwall.nhs.uk/specialparentingservices](http://www.cornwall.nhs.uk/specialparentingservices)**

**Telephone: 01872 356040**

## Summary

### Helping parents to engage with other agencies

Professionals can help parents engage positively with other services, by:

- Building up their confidence
- Providing them with ongoing emotional support
- Helping parents understand the role of workers in different services
- Ensuring professionals agree expectations of the knowledge and skills needed by parents, so that parents understand what is required
- Helping parents attend 'mainstream' services, like Home-Start or Sure Start
- Ensuring a positive, competency promoting, assessment is carried out so other agencies understand parents' skills as well as their support needs
- Mapping local services for parents and their children to encourage their involvement.

### Advocates

- Specialist advocacy services support parents with learning difficulties, either generally or in relation to child protection and court proceedings
- Independent, non-judgemental advocates can negotiate with all parties and challenge services, when necessary
- Advocates need understanding of all the systems (both adult services and child protection) they are involved with
- The advocacy role is taken on by many workers who are not themselves employed as advocates, to ensure parents' voices are heard
- Professionals need a greater awareness of the potential role for advocates in supporting parents with learning difficulties.

### Multi-agency working

- **Multi-agency support means:**
  - Clearly planned and coordinated support services
  - More consistent support
  - Reduced parental stress and improved parental engagement

- **Multi-agency support can come from:**
  - A specialist ‘parents with learning difficulties’ service which does all the work
  - Initial ‘crisis’ work by a team (specialist or from within a community learning disability team) and then ongoing support from another agency
  - A ‘virtual’ team of relevant professionals who support as and when appropriate
- **Effective multi-agency working requires:**
  - A shared desire on the part of all those involved to see parents achieve
  - Understanding of each others’ areas of responsibility and ways of working
  - Sharing of tools to support parents’ skill development
  - Development of joint protocols/policies/care pathways
  - Regular meetings and ongoing communication
  - Workers experienced in supporting adults with learning difficulties acting as a resource to other staff
  - Keyworking (ie one professional liaises with the parents and between different professionals and agencies).



# Chapter 8 Child protection and the courts

***Our first court was quite good for us. Got more or less what we wanted, extra visiting times... Three judges agreed that two hours on two days a week was unacceptable. They listened.***

(Couple with learning difficulties)

## Introduction

This chapter looks at the important issue of ensuring the welfare and safety of the children of parents with learning difficulties. It looks initially at the need for appropriate and ongoing support to parents in order to minimise the risk of child protection issues arising; training and support for staff and at the role of *Child in Need* meetings. It then reviews the range of issues arising in the child protection and court systems: the difficulties parents encounter; the support they need; the role of advocates and children's Guardians; and the support needed by professionals.

## 1. Ensuring children's welfare – by providing the right support

Professionals involved in this study were clear that the provision of support for parents with learning difficulties was fundamental to ensuring the welfare and safety of their children (cf. Morgan & Goff, 2004).

***...keep the child safe but also making sure that there is someone there for mum.***

(Support worker)

Professionals were also trying to work proactively with parents to prepare them for the next stage of their parenting responsibilities and prevent any difficulties from developing into child protection issues. The aim of a number of parenting groups and drop-in sessions for parents with learning difficulties (see Chapter 6) was to provide such ongoing support for parents.

## Raising concerns

Professionals (including advocates) who were supporting parents with learning difficulties were clear that the protection of the child or children was of paramount importance. Indeed one worker in services supporting adults with learning difficulties said she would be offended if her professionalism were questioned to the extent that other staff did not believe she would put child protection first. Another put it like this:

***We respect your rights as a parent but we respect the right of the child to be looked after properly and if that is in jeopardy then we will support children and families [services].***

Staff supporting parents with learning difficulties stressed that they were very clear with parents that they would report child protection issues to children and family services. One professional described how her community learning difficulties team had done this:

***We made the initial report to say that actually we are really concerned, it was us who pushed it and pushed it because we really didn't feel the child was safe. We had huge concerns and no amount of support was going to address that. A lot of support had already gone in ...yet we actually managed to be there on the day of court supporting that woman and actually sitting beside her in court explaining what was happening.***

(Community nurse based in a community learning disabilities team)

One advocacy service said they had an agreement with parents about how they would raise concerns they had about their children. This agreement was based on the *Protocol on Advice and Advocacy for Parents* (Lindley & Richards, 2002).

In some cases, involvement in the child protection system was felt to have helped some parents understand that there was a difficulty with their parenting and to respond accordingly. Indeed, some workers in services supporting adults with learning difficulties discussed supporting children and family teams to initiate child protection proceedings when necessary.

## **Child in Need meetings**

Sometimes when there were concerns about the welfare of children, workers supporting parents with learning difficulties called *Child in Need* meetings to raise awareness of potential child protection issues and plan support for the family accordingly. *Child in Need* meetings were used before entry into the child protection arena to formalise the issues perceived and the involvement of relevant professionals, including teachers. One community nurse noted that 'anyone could call a meeting', which would deal with 'the nitty gritty stuff', 'enable parents to get the help and advice they need' and to 'build a support network around the family.'

***We set up a meeting before child protection conference to help parents get support. Services are often panicking and don't know how to help. We explain that parents don't understand and show them [staff in other agencies] how to communicate.***

(Community nurse)

Staff believed that calling a *Child in Need* meeting had a number of advantages. The meeting:

- Had to be attended by parents
- Ran to a set format of identifying needs and how to meet them
- Set a timetable for action
- Was less threatening for parents than a child protection meeting
- Enabled professionals to gauge whether parents were willing to engage informally with support, or whether more formal child protection proceedings were required.

## Child protection training and support for professionals

As recommended by McConnell and Llewellyn (2002), many of the workers involved in the study had had child protection training so that they were aware of potential child protection issues and could contribute appropriately to the child protection process:

***We attend case conferences and we're expected to give our recommendation ...someone with absolutely no experience of child protection going along to the case conference and being expected to say yes or no, I mean it's dangerous.***

(Social worker working with adults with learning difficulties)

Managers were very aware that their staff needed support in this area. Clinical supervision and access to child protection nurses, midwives or advisers, in addition to attendance at child protection training, was common, as well as ongoing peer support and wider support from multi-agency groups and meetings. One specialist team has set up monthly team supervision, as well as:

***...the traditional supervision, by somebody completely out of the team, completely removed from the family, to question what you are doing, or why you are still doing that. It just gets you to refocus and rethink, well are we doing the right thing and if we're not, what do we need to do?***

## The need for ongoing support

If parents become involved in the child protection process, they are likely to receive support from children and family services. Some professionals involved in supporting adults with learning difficulties mentioned their concerns that these parents could fall into a vicious cycle. While they were in the child protection process, and therefore being provided with support, they were able to fulfil the expectations of children and family services. However, once they had met those expectations, support from children and family services was likely to be reduced. At this point, the parents were likely to fail to meet expectations – and thus a vicious cycle ensued where they might then be put back on the child protection register.

## 2. Child protection and the courts

Recent research indicates that parents with learning difficulties are disadvantaged during the child protection and judicial processes by the way the child protection and judicial systems work – ie the rules of evidence and procedures; the inadequacy, and lack of availability of support services to parents before, during and after child protection and/or court proceedings and their own lack of understanding of the system.

There is also some consensus that parents with learning difficulties may be judged by stricter criteria than other parents; have evidence used against them which would not be used against other parents and be less likely to have received support in their parenting. If support has not helped, parents have tended to be blamed for the failure, rather than the inappropriate services (Booth & Booth, 2004; Booth et al, 2005a & b; McConnell & Llewellyn, 2000).

Parents involved in this study felt that social workers assumed that they could not be successful parents and just wanted to take their children away. They commented that in child protection proceedings and in the courts:

***Social workers have all the power. As a parent you are there, alone and not listened to.***

(Parent with learning difficulties)

## **Supporting parents through child protection and court proceedings**

Staff supporting parents with learning difficulties were frequently involved in the child protection and court systems, where the disempowerment and lack of understanding of parents with learning difficulties was most exposed. They were using a number of strategies to make the child protection and court processes more accessible, including:

- Developing accessible leaflets/videos about the child protection process (eg Skills for People, 2004)
- Producing an accessible information sheet explaining confidentiality
- Ensuring that there was a comprehensive, positive, competency promoting, assessment of parents' skills and abilities as well as their support needs (including a psychological assessment by a sympathetic psychologist)
- Providing parents with pictures of everyone at the child protection meetings/judicial proceedings
- Ensuring parents understood each professional's role
- Holding the child protection conference away from social services offices
- Making the child protection conference more friendly through small gestures, such as providing everyone involved with refreshments
- Developing guidance/a protocol for professionals on supporting parents to engage with the child protection process.

In one area, guidelines had been introduced to ensure the accessibility of child protection meetings. The guidelines specified that professionals should provide reports at least a week ahead of meetings, preferably with an easy to understand summary and only necessary professionals should be invited to the meetings.

### **Making Information Easier to Understand**

One child protection conference chair always asks for a parents' 'word bank'. This includes the words that the parents can read and understand. All subsequent letters to the 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.

Professionals and advocates were also endeavouring to ensure that the child protection and court systems took into account each family's wider context:

***As a psychologist I also do assessments for courts in child protection cases. I try and emphasise parents' strengths and competencies and draw attention to structural issues which need attention. I make suggestions about ways of supporting parents and highlight past deficiencies in support.***

(Clinical psychologist)

## **Parents and Children: Rights and Responsibilities in Court**

The rights of the children and their parents have to be balanced in court.

A parent with learning difficulties has the right for the court to consider seriously their ability to care for their children. But the court is right to look also at the responsibilities of the parents, and whether they can be responsible in the ways that are needed by their children. A judge told us that, from the court's viewpoint:

***Children have rights, adults have responsibilities.***

At the moment there is no definition of 'good enough' parenting, but courts should see it as ranging across basic care, security, routine, stimulation, and education throughout a child's childhood (ie to 16), not just for the immediate future. At the same time, children have a need to be with their birth parent.

In this judge's experience, cases around parents with learning difficulties could be the most emotionally disturbing to deal with:

***They love their children even more than we love ours.***

Some solicitors and judges were also attempting to support parents through the process. One solicitor stressed the importance of:

- Ensuring the most appropriate assessments were put before the court
- Slowing down the court process, so that parents were given the chance to show whether they could develop the appropriate skills and knowledge
- The Guardian's role, as they were independent and charged with determining what was best for the child (see below).

This solicitor strove to put the parents' views across in their own words, for instance, using the parent's words verbatim in their statement to the court rather than using 'lawyer words.' While this strategy was considered 'novel' by colleagues, the solicitor felt that the court system would gradually become more accessible as more parents with learning difficulties went to court.

Some judges were also trying to improve parents' experiences. One judge had asked for a parents' assessment to be carried out using the *Parents Assessment Manual* (McGaw et al, 1998). Another observed that:

***Courts must not rush to judge, but must gather all the evidence as quickly as reasonable.***

## **Making Courts Less Frightening**

Courts are very variable and dependent on the particular judge sitting. The emphasis is usually on speeding things up, to make decisions more quickly, but with parents with learning difficulties more time is needed.

A court can be a particularly frightening and threatening place. One judge we spoke to felt that this could be eased by a number of strategies: always smiling and greeting people; always talking to people in court; welcoming them in a friendly manner; and looking parents in the eye. He felt that where possible, courts should be on one level in a horseshoe shape, so that parents were beside their lawyers, not behind them, and everyone was close to each other.

He suggested that everything should be broken down into simple sentences; that special attention should be paid to the language being used, and jargon and long words avoided wherever possible. Parents should be encouraged to feel that it was all right to give evidence. He was prepared to jump on counsel or social workers who were aggressive in questioning: it was not necessary!

Support for parents in court is extremely important. Sometimes the court is asked to direct the local authority to provide support to the parents, but the court can only ask for this, not direct it. Some professionals, however, felt that judges had, on occasion, thrown cases out of court because adequate support had not been provided to families.

An independent expert highlighted the complexities of the official solicitor system. She felt that there needed to be further investigation into the role of the official solicitor (allocated to parents regarded as being unable to instruct their own solicitor) as the official solicitor could not be dismissed by parents if the relationship was not satisfactory, or if the solicitor was not felt to be working in the parents' best interest.

## **Advocates in court**

The guidance on *Working together to safeguard children* (DH, 1999) indicates that local authorities should work with parents at every stage of the child protection process. Many professionals felt that an advocate should be available to parents as soon as the child protection process was initiated. The *Protocol on Advice and Advocacy for Parents* (Lindley & Richards 2002) confirms that:

***...although parents do not as yet have a statutory right to involve an advocate on their behalf in a child protection case, there is never the less a strong presumption that they should be able to. (p3)***

One advocate clearly described the importance of their role during judicial proceedings:

***Advocates have a distinct role in explaining what is happening in court. The judicial system is wholly inaccessible, and a great deal of time and effort is expended in explaining what is going on, what is going to happen, who the different parties are, and what their roles are. A lot of time gets taken up in explaining outcomes and what people have to do – which may be detailed inaccessibly in conditions or agreements set by the court or social services.***

(Advocate)

Advocates felt that their role within child protection/judicial proceedings included:

- Reminding people to communicate appropriately
- Ensuring that agencies had explained issues clearly
- Supporting parents to speak, or speaking on their behalf if necessary
- Ensuring parents had access to reports, time to discuss the reports and an opportunity to put forward their own views
- Keeping a diary of meetings and a record of phone calls and conversations
- Receiving copies of all information sent to parents, if possible
- Making notes for parents and/or providing them with paper and pen during meetings
- Having a good understanding of the child protection process
- Knowing a knowledgeable and sympathetic solicitor
- Engaging solicitors when necessary and supporting parents to meet with them and to attend court
- Reinforcing to parents important messages from their legal team
- Explaining what was happening in court
- Providing emotional support for the parents.

This could take a good deal of time; parents might need four or five sessions to take on board information about court proceedings. One mother was so flustered about meeting her solicitor that she forgot to tell her solicitor about the domestic violence she had experienced until reminded by her advocate. (For more on the role of advocates generally, see Chapter 7).

## **Advocacy and the Courts**

One advocate said that she has learned that she needs to know in advance what will happen in court, and is well prepared so that she can help parents prepare. As soon as the solicitor knows which court the hearing will be in, she texts the advocate, who phones the parents. This helps dissipate the couple's

continued overleaf

anxieties about where the advocate will park, the amount of change needed for parking, how far they will need to walk, etc, allowing them to focus on the hearing. With all the parents the advocate is scrupulously honest about the possible outcomes. If the solicitor thinks it likely that the child will be taken into care, the advocate tells them, so that they can be prepared for this eventuality.

Parents' attendance at court was facilitated by advocates and workers through:

- Visiting the court prior to the case
- Using special measures, including a break in sessions and permission that parents need not enter court until they were required
- Explaining the advocates' role to the court.

## Children's Guardians

Children's Guardians are employed by the Child and Family Court Advisory and Support Service (CAFCASS) to look after the interests of children involved in family proceedings. They work with children and their families, and then advise the courts on what they consider to be in the children's best interests. Judges have to justify themselves if they disagree with the Guardian's views. The Guardian is often the professional who is with the family over the longest period of time.

According to one solicitor, a Guardian can make or break a case for the parents. They can be good allies as they are generally better informed than an ordinary social worker, and are independent. They are very experienced social workers and can influence and critically appraise local authorities but cannot provide resources. The children's interests have to be given precedence over those of the parents by Guardians, who recognise that it is often in the child's best long term interests to remain living, or in contact, with their family.

## The Role of the Guardian

In one case, where a Guardian was involved over a number of years, four children were removed from a mother with learning difficulties after substantial neglect and emotional damage. There were concerns that the eldest child would not recover. The Guardian recognised that, regardless of the damage, the emotional ties between the children and the mother were particularly strong, and greater damage would be done if contact between them were stopped.

The children were placed together in foster care, and the mother encouraged to have an ongoing role in their lives – not just in terms of visits, but in decisions affecting their lives. The outcomes for everyone, including the mother, were good, with all the children completing their education and becoming more confident and outgoing. She could continue to be a mother to them, just not on a full time basis.

It is vital for professionals to plan for different ages. Often parents can cope, and people are more helpful when the child is very young, but a great concern for CAFCASS is that ongoing needs assessment and planning continue as the child grows up. The funding and resources need to be there for the duration of childhood, not just in infancy.

***What damage will it do everyone if the parents bring the child up to age 4 or 5, and then the child has to be removed because of lack of support?***

(CAFCASS regional director)

## **Training professionals involved in child protection and judicial proceedings**

Workers from services supporting parents with learning difficulties were aware that they themselves needed support when involved in child protection and judicial processes. Child protection, legal report writing and court-craft training were required. Normal rules of confidentiality do not apply during judicial proceedings and reports intended only to inform colleagues can be used as evidence in court:

***You need to be careful how you write reports. I had a barrister assume a parent was doing something wrong because I hadn't been specific. You need to make clear if it is right or wrong and not leave room for questions.***

(Community nurse)

This professional recommended that all comments in a report should be self-explanatory and supported by evidence, so that they would not need to be called to court.

## **Summary**

### **Ensuring children's welfare by providing the right support**

- Ongoing support to families can prevent difficulties becoming child protection issues
- Respect for the rights of the child is a legal obligation for all staff
- A *Child in Need* meeting can be a useful vehicle for planning support for a family where there are potential child protection concerns
- Professionals need specific supervision and support on child protection.

### **Child protection and the courts**

- A number of strategies are needed to help parents through child protection and court proceedings
- Parents need an advocate or other support during their case
- Clear explanations and/or easy to understand information for parents about the process are important

- The different professionals involved, and their roles, also need to be explained to them
- Parents with learning difficulties need more time with solicitors so that careful explanations can be given – and understood
- Visiting court beforehand can be helpful
- Staff need training in report writing and court appearances
- Solicitors need to ensure that appropriate reports are put before the court and that the process is slowed down to give parents a better chance to understand and participate
- Judges cannot force local authorities to provide appropriate services. However, in some areas they are becoming more aware of the need for positive support for parents and for competency-based assessments.

## Chapter 9 Conclusions and recommendations

*If you've got kids you should treasure them. You don't know what you've got till it's gone... It means everything to us... We're not making any more mistakes.*

(Couple with learning difficulties)

### Introduction

In this final chapter we explore four key areas that have emerged in the course of this project, and then set out recommendations and ideas for improving support to parents with learning difficulties.

The chapter is structured into the following sections:

- **Parents with learning difficulties today**
- **Parenting with support: what does it mean in practice?**
- **Parenting with support: the barriers**
- **Parenting with support: moving from margin to mainstream**
- **Improving support to parents with learning difficulties and their children: some recommendations**

A separate executive summary of the main findings from the project can be found at the front of this report (or at [www.bristol.ac.uk/Depts/NorahFry](http://www.bristol.ac.uk/Depts/NorahFry) or [www.baringfoundation.org.uk](http://www.baringfoundation.org.uk)).

### 1. Parents with learning difficulties today

Parents with learning difficulties have been around for a long time, though when the first UK literature on them appeared (Craft & Craft, 1979) their public profile – and numbers – were low.

Over the last twenty years, however, adults with learning difficulties have increasingly become involved in close personal relationships, in the same way as their non-disabled peers – despite the barriers to achieving such relationships – and are also becoming parents.

Whatever their numbers in the population (see Chapter 1), it is clear from the enthusiasm with which this project was greeted that there is enormous interest in discovering the best ways to support parents with learning difficulties and their children, and the professionals involved with them. Even more marked is the apparent shift in attitude amongst much of the media, illustrated most graphically by the *Daily Mail* campaign, also referred to in Chapter 1. In this campaign previous assumptions that adults with learning difficulties could not – indeed, should not – ‘parent’ appear to have

shifted to questioning why appropriate levels of support are not provided to them so that they can parent successfully, and why their children should so often be taken into care.

The report on a national inspection of services to support disabled parents (including parents with learning difficulties) revealed that services to support disabled parents were patchy, underdeveloped and of variable quality (Goodinge, 2000). There was little evidence of coordination between services, even within the same local authority. Social work teams focusing on adults failed to record if those adults had a parenting role, while children's teams neglected to report if a parent was disabled. A holistic approach to supporting disabled parents was not in evidence. In the absence of appropriate, supportive, services, disabled parents were understandably wary of approaching social services teams, for fear that this would be seen as an admission of failure, and that it might increase the risk of their children being taken into care.

Five years later, and in the wake of policies on learning difficulties which explicitly identify the need and right of parents with learning difficulties to have access to appropriate support (eg DH, 2001; Scottish Executive, 2000), there has been a noticeable increase in services, and initiatives, aimed at supporting adults with learning difficulties and their children.

In at least one minority ethnic community visited as part of this study, marriage and parenting were expected of adults with learning difficulties even where the individual might be described as having quite serious impairments. In this community, the concerns of workers in services focused more on ensuring the adults' ability to consent to marriage and sex (often with a non-disabled partner) than on the need to safeguard their children, who were being brought up in a dedicated, extended family (see Box, Chapter 6, Section 7).

In this area, workers were engaging with families to discuss the issues whenever possible prior to marriage. Subsequently workers might be involved in supporting the disabled parents' rights, including their involvement in bringing up their children. In many instances, as an interview with a mother at her day centre demonstrated, the parent with learning difficulties was largely excluded from parenting, the children being brought up by their non-disabled partner or grandparents. There will be a wide variety of course, of practices amongst different ethnic communities. Even within the same ethnic groups there will also be differences according to geographical location (urban/rural) and the age and circumstances of the parents concerned.

Nonetheless, even with the increasing acceptance that adults with learning difficulties might have the same rights to have children as other parents, the statistics on the numbers of children who are removed from parents with learning difficulties remain distressingly high (see Chapter 1). Yet children of parents with learning difficulties rarely enter the child protection system as a result of abuse by their parents. Almost always the prevailing concerns centre on a perceived risk of neglect, both as a result of the parent's intellectual impairments, and the impact of the social and economic deprivation commonly faced by adults with learning difficulties.

The picture which emerged from our research is of parents who are widely recognised as loving and deeply committed to their children, and wanting the best for them. But the disadvantaged and stressful circumstances in which they live conspire to make successful parenting a great challenge. If adults with learning difficulties are really to be given the same chance to be parents as other adults in our society, then they need access to services which will support them in their parenting role, so that they are able to successfully 'parent with support'.

## 2. Parenting with support: what does it mean in practice?

A key concept which has emerged from this research has been that of 'parenting with support'. At its simplest, this means working with adults with learning difficulties to provide the support they need, so that they can show whether or not they can become 'good enough' parents, rather than automatically assuming that they are destined to fail. The professionals and advocates who contributed to this study were endeavouring to overcome the 'disabling barriers' confronting parents with learning difficulties and their children. Recent work by Hedy Cleaver and Don Nicholson (2005) suggest that parents with learning difficulties may now be *more* likely to receive ongoing support from services than other parents involved in the child protection process – and that their cases are more likely to remain open (Cleaver & Nicholson, 2005).

Services and schemes that have mushroomed around the country in support of parents with learning difficulties are responding to the principles and guidance contained in a range of legislation and policy guidance. These include The Children Act (with its emphasis on supporting families so that children can remain with them); *Valuing People* (DH, 2001); *The Same as You?* (Scottish Executive, 2000); obligations under the Disability Discrimination legislation to make public services accessible to disabled people (including parents with learning difficulties) and the requirement in the *Fair Access to Care Services* policy guidance (DH, 2002), that local authorities should include an individual's social tasks and responsibilities, including their role as a parent, when thinking through their eligibility criteria for services. In one area of Northern Ireland professionals had been advised that the Human Rights Act meant that they must show that they were providing support to parents. As a result, one respondent in our study said she had not had a child protection case come to court for a number of years.

The professionals and supporters we encountered were trying to support adults with learning difficulties to interact positively with the services involved with them and their children in three main ways:

- **Raise awareness about parents with learning difficulties and their support needs**
  - amongst professionals working in generic services, and acting as a source of expertise for them, while also supporting parents to go to mainstream groups and access services that were not learning disability specific
- **Develop multi-professional and multi-agency support for parents with learning difficulties and their families through:**
  - keyworking (where one worker is responsible for coordinating support to a family and liaising with parents)
  - clear communication
  - consistency of approach
  - joint training
  - shared concepts of parenting
  - joint/inter-agency protocols on working with parents with learning difficulties
  - the development of care pathways

- the provision of training in child protection for those working with adults with learning difficulties
  - training for those working in children’s services in understanding and communicating with adults with learning difficulties.
- **Empower parents with learning difficulties by:**
    - providing easy to understand information
    - being consistent, clear and honest in their interactions with the parents and with other professionals
    - undertaking competency based assessments and providing competency building support
    - enabling parents to develop their skills, support each other, share their experiences and have their voices heard.

A key factor in moving forward in the provision of multi-professional and multi-agency support to parents with learning difficulties will remain the priority given to the protection and welfare of children. Our findings indicate that ongoing support for parents with learning difficulties will also fulfil a preventative function, contributing to the safeguarding of their children. The involvement of independent advocates is also critical in enabling the needs of parents and their children to remain centre stage, regardless of the role boundaries and constraints of different professionals.

Successful joint working seems likely, on the basis of this study, to lead to a ‘virtuous’, rather than ‘vicious’ cycle: as trust and respect are developed between professionals and between teams, so future joint working becomes easier and the prospects for parents with learning difficulties and their children more positive.

### **3. Parenting with support: the barriers**

The evidence from research and practice underlines the fact that parents with learning difficulties are among the most disadvantaged groups of parents in our society, socially and economically, with all the stresses in daily living that this implies. Such stresses are recognised as having a negative impact on parenting ability. The provision of appropriate support aims to break this cycle by reducing the negative stresses on parents, improving their self confidence and esteem and increasing their social connections and networks and access to community resources.

The concept of ‘parenting with support’ has been developed from this relatively small-scale study, drawing on responses, and invitations to visit, from interested professionals, parents, supporters, organisations and agencies. Although it would be unwise to generalise from our findings (see Appendix 1) there does appear to be evidence of developments in this direction at grassroots level, as services around the UK attempt to support parents with learning difficulties and their children in a variety of ways. There are, however, a number of barriers which may inhibit the spread of ‘parenting with support’ from the margins to the mainstream of service provision.

Firstly, many of the services and schemes discovered in this study were not linked up with each other. Individual initiatives had often come into being as the result of championing by key individuals, often in the wake of a court case or some other negative experience relating to a parent with learning difficulties in the local area.

Such individuals were clear that support for parents with learning difficulties should now be a priority in their services and had managed to get this belief translated into policy and practice locally, with support at a higher level of their agency or organisation. But without ready access to a national forum or network, like the Disabled Parents Network (see Box), those developing support services are at risk of 'reinventing the wheel' again and again.

## Disabled Parents Network

Disabled Parents Network (DPN) is a national organisation of and for disabled people, including people with learning difficulties, who are parents or who hope to become parents, and their families, friends and supporters.

DPN operates a telephone help line run by disabled parents, produces a quarterly newsletter and has compiled ten information briefings to assist disabled parents with a range of issues, including: what the law says; services; getting your needs assessed; making a care plan; direct payments; making a complaint etc, which are free to disabled parents. To raise awareness of the issues for disabled parents DPN provides disabled parents as speakers, workshop leaders and also provides training. Their website contains a resource directory consisting of frequently asked questions and other sources of information, fact sheets and books for and about disabled parents. DPN also run a web-based public forum and a separate research forum to promote and publicise research about disabled parents. For more information:

**Telephone: 08702 410 450**

**Email: [information@disabledparentsnetwork.org.uk](mailto:information@disabledparentsnetwork.org.uk)**

**[www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)**

A second barrier can be the lack of experience, expertise or confidence of relevant professionals. Many of those involved in our study highlighted the key role of community nurses here, for example, though there is some evidence that they (like other professionals providing support to parents with learning difficulties) do not always feel well equipped to undertake this role (Genders, 1998; McGaw, 1996). Similarly, as we have seen, social workers in children's services often lack experience in dealing with adults with learning difficulties, while those working in adult services lack knowledge about children's services and child protection. Professionals in adult services may also be inhibited from providing support to parents out of a reluctance to get involved in court processes, or because supporting parents is felt to be just one of many priorities for adult services, and one which is, moreover, not adequately resourced or included amongst performance indicators. The lack of independent advocates (paid or voluntary) can also pose difficult role conflicts for professionals supporting parents with learning difficulties who are involved in child protection procedures, while the lack of awareness around parents with learning difficulties in mainstream services, can further inhibit planning for and provision of effective support.

Some of those involved in our study felt that a move towards 'family teams' would offer the best way forward for ensuring positive support for parents with learning difficulties and their children. However, current structural changes in local authorities mean that children's services are integrating with education and other services while local authority adult social services integrate with health care provision (DfES, 2003a; DH, 2005). Such changes seem more likely to work *against* better coordination between children's and adult services involved with families where parents have learning difficulties, rather than *towards* it.

The Green Paper on the future of social care for adults in England, *Independence, Well-being and Choice*, has a welcome emphasis on the need for preventative support for all vulnerable adults (DH, 2005). Currently, however, the provision of preventative support of the kind most needed by parents with learning difficulties is severely inhibited by eligibility criteria. Many parents with learning difficulties needing support are regarded as 'too able' to receive such support from adult services (Morris, 2003; DfES, 2003a). Many will not previously have had contact with local services. For them, becoming a parent may mean referral to services at a time of crisis – precisely when it is more difficult for them to be able to demonstrate that they can be 'good enough' parents, and when appropriate support may not be readily available.

As becoming a parent is a major life event, some services, encouragingly are noting it as a criterion for social service provision, and thus a trigger for the kind of preventative support that parents require.

For many disabled people, including disabled parents, access to direct payments (where individuals assessed as being eligible for a particular service can, instead, choose to receive the cash equivalent, in order to purchase and arrange the support they need) is seen as a particularly helpful way of 'finding the right support'. In the course of this study, however, there was little evidence of direct payments being accessed by parents with learning difficulties. It would be helpful if more research, or development work, could be done in this area.

#### **4. Parenting with support: from margin to mainstream?**

So what would be needed to accelerate the shift away from the negative assumptions and attitudes perceived, and experienced, by parents with learning difficulties in their quest to be 'good enough' parents to their children? How can they be helped towards a situation where they are enabled to parent successfully with the provision of appropriate support?

Of key importance is the provision of preventative support. Such support can lessen concerns around child protection, reduce the stress on parents, boost self confidence and enhance the ability to parent successfully.

Chapters 5 to 8 provided detailed examples of how support needs to be provided to parents both at an individual level and at a service or area level. The literature consistently highlights the need for children's and adult services to work together in a pro-active and preventative way to meet the needs of the whole family (Morris, 2003). National guidance in this area will be welcome.

A variety of other issues also need to be addressed, for example:

- The roles and boundaries of different professionals and services involved with a family and how they can work together (local protocols are an important way forward here)
- What level of support should be provided – and by whom
- Appropriate and explicit care pathways
- Local systems to ensure consistent concepts of parenting are used by the different professionals involved with parents
- How support for parenting can be accessed in the absence of a concern around child protection or a child in need

- The training required by professionals in children, adult, family support and generic services
- Ensuring that generic services, such as Home-Start and Sure Start, are informed and equipped to work effectively with parents with learning difficulties
- Provision of funding for support services, especially advocacy for parents with learning difficulties involved in child protection and judicial processes
- Sharing of examples on how eligibility criteria which include parenting support, as recommended by the *Fair Access to Care Services* guidance (DH, 2002), operates in practice
- Guidance on how families can be supported holistically as children and adult services are reorganised in divergent ways.

In addition, some reassurance in response to concerns that the Adoption and Children Act 2002 will result in more children being removed from parents with learning difficulties would be welcome. More sharing is also needed of what works in supporting parents with learning difficulties and their children, including evaluations of different service initiatives (see McGaw & Newman, 2005 for a summary of evaluations of different parenting interventions).

The following, final, section of the report summarises key recommendations for improving services in the future to parents with learning difficulties and their children.

## 5. Recommendations

Here, we distil some core recommendations emerging from the study on how services for parents with learning difficulties and their children can be improved in the future. For the sake of clarity, we have grouped them into four categories even though these clearly overlap:

- What is needed at national (policy) level?
- What needs to be available at a local level?
- What needs to be available for individual parents with learning difficulties and their children?
- What further research or development projects are needed?

### (i) What is needed at national (policy) level?

**1. Practice guidance:** joint DfES/DH practice guidance for children's and adult services on working together to support parents with learning difficulties and their children.

**2. National training programme:** funding for a national training programme on supporting parents with learning difficulties and their children for professionals in both learning disability and children's services.

**3. Standards, targets and performance indicators:** CSCI (Commission for Social Care Inspection) standards to include the criterion that if parents with learning difficulties have their children removed from them, this is *not* because of lack of support from adult services. (Such a standard was included in the previous national inspection of

learning disability services: standard 2, criterion 2.8; SSI, 2001). Appropriate performance indicators to be introduced.

**4. Advocacy:** increased, ongoing, funding for advocacy services to support parents with learning difficulties, especially when involved in child protection and judicial processes.

**5. Guidelines:** on the involvement of parents with learning difficulties in child protection and judicial processes.

**6. Support to develop a national network:** sharing good practice around supporting parents with learning difficulties.

**7. Demonstration and dissemination:** more demonstration/pilot projects on supporting parents with learning difficulties to be funded and evaluated, with good practice disseminated.

**8. Accessible information:** such as *You and Your Baby*, the accessible book produced by CHANGE (Affleck & Baker, 2004), to be made more widely available to parents with learning difficulties and the services supporting them.

**9. Resources for professionals:** the Barnardo's publication *What Works for Parents with Learning Disabilities?* (McGaw & Newman, 2005) to be widely distributed to all children's services and adult learning disability teams.

**10. Government departments:** issues relating to young people with learning difficulties to be included in work by the Social Exclusion Unit and the DfES on teenage pregnancies. Officials from all the relevant government departments (eg. DfES Safeguarding Unit, DfES Family Division, Valuing People Support Team, DH Disability Policy branch, DH Women's Health and Maternity Team, The Office for Disability Issues) to meet and work together to improve services to parents with learning difficulties and their children.

**11. Direct payments:** dissemination of advice (and possibly targets) around the use of direct payments to support adults with learning difficulties to help them parent.

## **(ii) What needs to be available at a local level?**

**1. Multi-professional and multi-agency working:** supported by joint training and strategy development; care pathways and protocols for joint working, including clarity over different professionals' roles and boundaries.

**2. Local, multi-professional, multi-agency forums:** for discussion and support.

**3. Keyworking:** to support parents with learning difficulties and their families.

**4. Training:** for staff in generic and family support services – on identifying and supporting parents with learning difficulties; and for staff working in specialist adult learning difficulty services – about child protection.

**5. Competency-based assessments:** (eg McGaw et al, 1998) and training in undertaking them.

**6. Skills training and other interventions:** access to a range of interventions, and expertise/training in delivering them in the parents' home.

- 7. A range of support services:** which can be provided, and funded, long term.
- 8. Group support:** through parents' groups, which also help to increase parents' social networks.
- 9. Partnership working with parents:** both in relation to bringing up their own children and also in the delivery of training or planning for the development or delivery of support services.
- 10. Close working with mainstream services:** identification and creation of effective systematic links between generic services, such as maternity services, doctors, schools, mainstream parenting projects and specialist learning difficulties teams, so that services do not have to wait for problems to arise, before parents can be assessed on their needs for support.
- 11. Joint working:** local learning disability trusts/social services departments and children's trusts to jointly fund posts to coordinate support to parents with learning difficulties and their families. This could be one person acting as a link between agencies or a specialist adult learning difficulty post within children's services and a specialist children's post within adult learning difficulty services.
- 12. Appropriate eligibility criteria for assessments for services:** many parents with learning difficulties do not currently reach the thresholds for community care services or support. They only show up on services' 'radar' if their children are seen as Children In Need or as being at risk. Local authorities need to be responsive to the fact that adults with learning difficulties may need an assessment, specifically triggered by their needs as parents. This is consistent with the *Fair Access to Care Services*' (DH, 2002) requirement that social roles (including parenting) should be included in the assessment. Procedures need to be in place so that children do not have to be perceived as clients of social services in order for their parents' support needs as parents to be met by local agencies.

### **(iii) What needs to be available for individual parents with learning difficulties and their children?**

#### **1. Easy to understand information:**

- about all aspects of parenting (The CHANGE book, *You and Your Baby*, 2004, is a helpful accessible resource)
- on the support available – whether from mainstream services, like maternity services, or a specialist learning disability team
- about child protection and judicial processes

**2. Advice:** parents frequently need advice in multiple areas of their lives, not just around the forthcoming baby. This includes advice on benefits and how to handle problems in relation to poor housing, harassment and so on.

**3. Skills teaching:** and other focussed help as necessary.

**4. Ongoing support:** adapted to changing circumstances as the child gets older and continuing if (and after) a child is adopted.

**5. Consistency and clarity:** from the professionals involved about their expectations of them as parents.

6. **Keywording:** so that parents are not confused by different interventions by different professionals.
7. **Advocacy:** whether professional or voluntary, to support parents, particularly if they are involved in child protection or judicial processes.
8. **Informal support:** eg via a Circle of Support or Home-Start.
9. **Encouragement and affirmation:** so that parents can gain the confidence to engage positively with services and demonstrate that they can be good enough parents with support.
10. **Contact with other parents:** for example through parents' groups, so that they can share skills and experiences.
11. **Parent involvement:** in the development of new services, training of professionals and other initiatives.

#### **(iv) What further research or development projects are needed?**

1. **Fathers with learning difficulties:** most of the research, literature and support and intervention services focus on mothers with learning difficulties, with the exception of small scale but illuminating studies from Iceland (Sigurjonsdottir, 2004) and Tower Hamlets in London (O'Hara & Martin, 2003) and a fathers group in South Norfolk (see Box, Chapter 7, Section 3). Our research, and the recent national survey, confirm that fathers with learning difficulties are heavily involved in parenting their children (Emerson et al, 2005). Research and further work in this area would be timely.
2. **Older children/teenagers:** Much of the existing research focuses on families with young children. What are the issues and challenges as children get older?
3. **Issues for parents with learning difficulties from different minority ethnic groups:** including issues of consent. (There has been very little in this area to date, with the exception of the small scale study reported by O'Hara & Martin, 2003).
4. **Direct payments:** how can they be used to support parents with learning difficulties?
5. **Courts:** how can they be made more accessible? What strategies can help members of the judiciary and parents with learning difficulties involved in court proceedings?
6. **Advocacy:** what makes for effective advocacy for parents with learning difficulties and how can this be provided?
7. **Support after adoption:** what is, or would, constitute good practice in this area?
8. **Parenting with support:** what services are needed to facilitate this and how are they best provided?
9. **Cost effectiveness analyses:** what are the respective costs – and or benefits – of placing and maintaining a child in care, as compared with the costs of providing effective support to the family so that the child can remain safely at home?

# References

- Affleck, F. (undated) *Planning a Baby*, Leeds, CHANGE
- Affleck, F. & Baker, S. (2004) *You and Your Baby*, Leeds, CHANGE
- Appleton, T., Clifton, R. & Goldberg, S. (1975) The development of behavioral competence in infancy. In Horowitz, F. (ed) *Review of child development research*, Vol 4, Chicago, University of Chicago Press
- Barlow, J. (1999) What works in parenting education programmes. In Lloyd, E. (ed) *Parenting matters: what works in parenting education*, Barkingside, Barnardo's
- Booth, T. (2000) Parents with learning difficulties, child protection and the courts, *Representing Children*, 13(3), pp175-188
- Booth, T. (2003) Parents with learning difficulties and the stolen generation, *Journal of Learning Disabilities*, 7 (3), pp203-209
- Booth, W. (2000) Parents with learning disabilities need support, *Nursing Times* 96, 23 (8), p41
- Booth, T. & Booth, W. (1998) *Advocacy for parents with learning difficulties: developing advocacy support*, York, Joseph Rowntree Foundation
- Booth, T. & Booth, W. (1999). Parents Together: action research and advocacy support for parents with learning difficulties. *Health & Social Care in the Community*, 7 (6), pp464-474
- Booth, T. & Booth, W. (2004) *Parents with Learning Difficulties: child protection and the courts, a report to the Nuffield Foundation on Grant No. CPF/00151/G*. Sheffield University, Department of Sociological Studies
- Booth, T., Booth, W. & McConnell, D. (2005a) Care proceedings and parents with learning difficulties: comparative prevalence and outcomes in an English and Australian court sample, *Child and Family Social Work*, 10 (4), pp353-360
- Booth, T., Booth, W. & McConnell, D. (2005b) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts, *Journal of Applied Research in Intellectual Disabilities*, 18, pp7-17
- CHANGE (2005) *Report of National Gathering of Parents with Learning Disabilities*, Leeds, CHANGE
- Cleaver, H. & Nicholson, D. (2005) *Children living with learning disabled parents*, (Unpublished), London University
- Craft, A. & Craft, M. (1979) *Handicapped Married Couples*, London, Routledge & Kegan Paul
- Culley, L. & Genders, N. (1999) Parenting by people with learning disabilities: the educational needs of the community nurse. *Nurse Education Today*, 19 (6), pp502-508
- Department for Education and Skills (2003a) *Every Child Matters*. London, The Stationery Office

Department for Education and Skills (2003b) *The Children Act Report 2002*. London, The Stationery Office

Department for Education and Skills (2005a) *CAF (Common Assessment Framework for children and young people): Guide for service managers and practitioners*.

**[www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)**

Department for Education and Skills (2005b) *How ICS, CAF and the IS index fit together*.

**[www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)**

Department for Education and Skills (2005c) *CAF Training for practitioners*.

**[www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)**

Department for Education and Skills/Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services*. London, DH

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London, The Stationery Office

Department of Health (2002) *Fair Access to Care Services*. **<http://www.dh.gov.uk>**

Department of Health, Home Office & Department for Education and Employment (1999) *Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children*. London, The Stationery Office

Department of Health, Home Office & Department for Education and Employment (2000) *Framework for the Assessment of Children in Need and their Families*. London, The Stationery Office

Department of Health (2005) *Independence, well-being and choice*. (Green Paper on adult social care), London, DH

Emerson, E., Malam, S., Davies, I. & Spencer, K. (2005) *Adults with Learning Difficulties in England 2003/4*, **[www.ic.nhs.uk/pubs/learndiff2004](http://www.ic.nhs.uk/pubs/learndiff2004)**

English, S. (2000) 'Parents in partnership' *Learning Disability Practice*, 3 (2), pp14-18

Feldman, M.A., Varghese, J., Ramsay, J., & Rajska, D. (2002) Relationships between social support, stress and mother-child interactions in mothers with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities*. 15, pp314-323

Genders, N. (1998) *The role of the community nurse (learning disability): Parenting by people with learning disabilities*, London, The Maternity Alliance

Goodinge, S. (2000) *A jigsaw of services: Inspection of service to support disabled adults in their parenting role*, London, DH

Green, G. & Vetere, A. (2002) 'Parenting, learning disabilities and inequality: can systemic thinking help?' *Clinical Psychology Forum*, 14, pp9-12

Hames, A. & English, S. (undated) *Re: Screening Tool Relating to the Assessment of Parents with suspected Learning Disabilities (also known as the Sanderson Screening Tool)* (Covering letter accompanying screening tool), Unpublished

- Kirby, J. (2003) The local supervising authorities in practice, *Midwives*, 6 (5), pp198-199
- Kroese, B., Hussein, H., Clifford, C. & Ahmed, N. (2002) Social support networks and psychological well-being of mothers with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities*, 15, pp324-340
- Lawrence, P & Wiffin, J. (2002) *Family group conferences: Principles and practice guideline*, Ilford, Barnardo's/Family Rights Group/NCH
- Lindley, B. & Richards, M. (2002) *Protocol on advice and advocacy for parents (child protection)*, Cambridge, Centre for Family Research
- Llewellyn, G. & McConnell, D. (2002) Mothers with learning difficulties and their support networks, *Journal of Intellectual Disability Research*, 46, pp17-34
- Llewellyn, G. & McConnell, D. (2005) You have to prove yourself all the time: people with learning disabilities parenting. In Grant, G., Goward, P., Richardson, M. & Ramcharan, P. (eds) *Learning Disability: A life cycle approach to valuing people*, Maidenhead, Open University Press
- Llewellyn, G., McConnell, D., Cant, R. & Westbrook, M. (1999) Support network of mothers with an intellectual disability: an exploratory study, *Journal of Intellectual and Developmental Disability*, 24 (1), pp7-26
- Llewellyn, G., McConnell, D. & Ferronato, L. (2003) Prevalence and outcomes for parents with disabilities and their children in an Australian court sample *Child Abuse and Neglect*, 27, pp235-251
- McBrien, J. & Power, M. (2002) Professional attitudes to supporting parents with learning difficulties *Tizard Learning Disability Review*, 7 (3), pp16-22
- McCarthy, M. & Thompson, D. (1998) *Sex and the 3R's*, Brighton, Pavilion
- McConnell, D. & Llewellyn, G. (2000) Disability and Discrimination in Statutory Child Protection Proceedings. *Disability and Society*, 15(6), pp883 – 895.
- McConnell, D. & Llewellyn, G. (2002) Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law* 24(3), pp297–317
- McConnell, D., Llewellyn, G. & Ferronato, L. (2002) 'Disability and decision making in Australian care proceedings' *International Journal of Law, Policy and the Family*, 16, pp270-299
- McDonnell, P. & Hames, A. (2005) Designing and piloting a screening tool relating to the assessment of parents with suspected learning difficulties *Clinical Psychology*, 46, pp19-21
- McGaha, C.G. (2002) Development of parenting skills in individuals with an intellectual impairment: an epigenetic explanation *Disability and Society*, 17 (1), pp81-91
- McGaw, S. (1994) *Raising the parental competency of parents with learning disabilities*, Unpublished PhD dissertation (Available from British Lending Library, Boston, Lincs)
- McGaw, S. (1995) *I want to be a good parent: the BILD parenting series*, Kidderminster, BILD  
[http://www.bild.org.uk/publications/book\\_pages/life\\_stages.htm](http://www.bild.org.uk/publications/book_pages/life_stages.htm)

- McGaw, S. (1996) Services for parents with learning disabilities, *Tizard Learning Disability Review*, 1 (1), pp21-32
- McGaw, S. (1997) Practical support for parents with learning disabilities. In O'Hara, J. & Sperlinger, A. (eds) *Adults with Learning Disabilities*. Chichester, John Wiley & Sons
- McGaw, S., Beckley, K., Connolly, N. & Ball, K. (1998) *Parent Assessment Manual*. Truro, Trecare NHS Trust  
**<http://www.cornwall.nhs.uk/specialparentingservices/patientassessmentmanual.asp>**
- McGaw, S., Smith, K. & Tomabene, A., (1999) *The Parenting Skills Cards*, Kidderminster, BILD  
**[http://www.bild.org.uk/publications/book\\_pages/life\\_stages.htm](http://www.bild.org.uk/publications/book_pages/life_stages.htm)**
- McGaw, S., Ball, K. & Clark, A. (2002) The effect of group intervention on the relationships of parents with intellectual disabilities *Journal of Applied Research in Intellectual Disabilities*, 15, pp354-366
- McGaw, S. & Newman, T. (2005) *What works for Parents with Learning Disabilities?* Ilford, Barnardo's
- Mencap (2005) *Making the Difference: A training pack for organisations working with parents with a learning disability*, The Parenting Fund/The Ann Craft Trust
- Morgan, P. & Goff, A. (2004) *Learning Curves. The assessment of parents with a learning disability: a manual for practitioners*, Norwich, Norfolk Area Child Protection Committee
- Morris, J. (2003) *The Right Support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role*. York, Joseph Rowntree Foundation
- Morris, J. (2006) *Supporting disabled parents: Knowledge review. Part 1: Literature review*. (1st draft of report for Social Care Institute for Excellence)
- Murshed, M. (2005) Good practice...parents with learning difficulties, *Disability, Pregnancy and Parenthood International*, 50, Summer 2005, pp16-17
- Newman, T. & Wates, M. (2004) *Disabled parents and their children: building a better future*. London, Barnado's
- O'Hara, J. & Martin, H. (2003) Parents with learning disabilities: a study of gender and cultural perspectives, *British Journal of Learning Disabilities*, 31, pp18-24
- Olsen, R. & Clarke, H. (2003) *Parenting and Disability: Disabled parents' experiences of raising children*. Bristol, The Policy Press
- Olsen, R. & Tyers, H. (2004) *Think Parent: Supporting disabled adults as parents*. London, National Family and Parenting Institute
- Olsen, R. & Wates, M. (2003) *Disabled Parents: Examining research assumptions*. Dartington, Research in Practice
- One Plus One, (undated) *Familywise Pack*, **[www.oneplusone.org.uk](http://www.oneplusone.org.uk)**
- Overton, R., Evans, K., Underwood, J., Bocking, G. & Shwky, J. (2004) *Strategy development for the support of parents with learning disabilities in Essex*, Essex Social Services
- Prime Minister's Strategy Unit (2005) *Improving the life chances of disabled people*. London, Cabinet Office

- Raafat, C. & Lucas, K. (1995) *Parenting Skills: A training pack*. Brighton: Pavilion
- Ray, N., Rubenstein, H. & Russo, N. (1994) *Understanding the parents who are mentally retarded: guidelines for family preservation programs*, New York, Child Welfare League of America, pp725-743
- Richardson, N. (2001) When parents have learning difficulties *Nursing Times*, 26 April 01, p40
- Rose, V. (1994) Health education for parents with special needs, *Health Visitor*, 67(3), pp95-96
- SCARE, (2005a) *Helping parents with learning disabilities in their role in parents* London, Social Care Institute for Excellence
- SCARE, (2005b) *Helping Parents with a Physical Disability or Impairment in their Parenting Role*. London, Social Care Institute for Excellence
- Social Care Institute for Excellence, (2006) *Support for disabled parents: Knowledge Review*. (Unpublished draft submitted to SCIE)
- Scottish Executive (2000) *The Same as You?* Edinburgh, The Stationery Office
- Sellars, C. (2002) *Risk Assessment in People with Learning Disabilities*. Oxford, Blackwell
- Sheerin, F. (1998) Parents with learning disabilities: a review of the literature *Journal of Advanced Nursing*, 28 (1), pp126-133
- Sigurjonsdottir, H. B. (2004) Intellectually limited fathers, their families and formal support services in Kristiansen, K. & Traustadottir, R (eds), *Gender and Disability Research in the Nordic Countries*, Lund, Sweden, Studentlitteratur
- Skills for People, (2004) *Working with parents with learning disabilities. A guide to child protection conferences*. Newcastle Upon Tyne, Skills for People
- Social Services Inspectorate, (2001) *Inspection of Services for People with Learning Disabilities*. London, Department of Health
- Swain, P. & Cameron, N. (2003) Good enough parenting: parental disability and child protection *Disability and Society*, 18 (2), pp165-177
- Tymchuk, A.J., Andron, L. & Tymchuk, M. (1990) Training mothers with mental handicaps to understand developmental and behavioural principles *Mental Health Research*, 3, pp31-59
- Wates, M. (2002) *Supporting Disabled Parents in their Parenting Role*. York, Joseph Rowntree Foundation
- West Berkshire Mencap (2004) *Partners in parenting: An audit of services for parents with learning disabilities in West Berkshire*, West Berkshire, Mencap
- Woodhouse, A., Green, G. & Davies, S. (2001) 'Parents with learning disabilities: service audit and development' *British Journal of Learning Disabilities*, 29 (4), pp128-132
- Young, S. & Strouthos, M. (1998) *First Steps to Parenthood*. Brighton, Pavilion



# Appendix 1: Methodology

## Advice and guidance

This mapping study was guided by national experts in the field and a group of committed parents with learning difficulties, contacted via Circles Network (as discussed in Chapter 1).

## The web-questionnaire

The web-questionnaire aimed to locate services supporting adults with learning difficulties in their role as parents and to understand the support provided by them. The questionnaire was developed through consultation with national experts and local professionals, via telephone discussions and attendance at a parenting forum.

The questionnaire covered the following areas:

- Information about the respondents completing the questionnaire
- The service/organisation where the respondent worked
- Services/support provided to parents with learning difficulties
- Priority afforded to supporting parents with learning difficulties
- Which (other) professionals were providing support/services
- Positive attitudes towards parents with learning difficulties encountered
- Negative attitudes towards parents with learning difficulties encountered
- Positive practice in providing support at each stage of the parenting process, including facilitating multi-agency working
- Barriers to providing appropriate support at each stage of the parenting process

The questionnaire was piloted with three local professionals and refined in the light of their responses. Copies of the questionnaire are available from:

**Beth Tarleton – 0117 331 0976** or **Beth.Tarleton@bris.ac.uk**

The questionnaire was located via the web address **www.rightsupport.org**. Paper versions of the questionnaire were also available from the Norah Fry Research Centre, University of Bristol or by email via [right-support@bris.ac.uk](mailto:right-support@bris.ac.uk). The existence and location of the web-questionnaire was widely promoted via numerous learning difficulties websites, networks and relevant professional journals.

The questionnaire was developed using an automated survey site (**www.survey.bris.ac.uk**), which inputs questionnaire responses directly into a database and which presents responses clearly for basic analysis.

The survey database was exported into Access (database) for further statistical analysis and subsequent qualitative content analysis. The survey responses were analysed overall and by respondent group (eg advocates, workers supporting adults with learning difficulties, workers in services supporting vulnerable parents etc). Professionals in children's services were underrepresented as respondents in comparison with professionals involved with adult or learning difficulty services.

## Telephone interviews

Twenty one phone interviews were carried out with professionals who had completed the web questionnaire. These professionals were selected on the basis of the examples of positive practice described in their web questionnaire, including the development of pathways or protocols, parents' groups, multi-agency support and working closely with other, mainstream, services or services supporting vulnerable families generally. The telephone interviews focused in more detail on the positive practice described and on strategies to support development in the field more widely.

## The case studies

Case study visits were made to six areas of the United Kingdom, in England, Scotland and Wales. (Although contact was made with relevant colleagues in Northern Ireland, it did not prove possible to organise a visit there in the time available, although professionals from Northern Ireland were involved in the study through the web questionnaire). The areas were selected to explore different examples of positive practice highlighted by respondents in the telephone interviews:

- Support provided by a national voluntary organisation
- An agency providing specialist assessments and support
- A specialist community parents with learning difficulties team (which was part of a wider community learning difficulties team)
- A number of services supporting parents with learning difficulties in one geographical region (including speech and language therapists, community nurses and adult social workers in community learning difficulties teams and a specialist team supporting parents with learning difficulties)
- A community learning difficulties team supporting adults with learning difficulties from a particular minority ethnic background
- A local authority in which two teams were comparing practice with a view to working more closely together and where the parents' group had made a video for professionals.

The visits were usually conducted over two days by one member of the project team. Interviews were carried out with relevant professionals from a variety of backgrounds. Visits were also made to local parenting groups and with individual parents or couples to find out the support they had been receiving from services.

The material collected from the case study visits was analysed in conjunction with the qualitative material derived from the telephone interviews and web-questionnaires.

## Appendix 2: What kind of services are supporting parents with learning difficulties? Tables and further information on questionnaire respondents

### 1. The respondents

The 85 questionnaire respondents – all of whom were either supporting parents with learning difficulties or developing services to support them – included professionals from a wide range of backgrounds: community nurses (17); advocates (17); psychologists (11); workers in adult services (9); occupational therapists (5). Respondents also included: a social worker in children’s services, a children’s nurse, a teacher, a direct payments worker, a supported living manager, a manager of support workers, a community development worker, 4 regional/area managers for social services or health, 2 chairs of charities and 1 parent with learning difficulties. (Information from parents was primarily collected face to face via interviews or group discussion). Professionals in children’s services were under-represented in comparison with those involved in adult learning difficulty services, since the questionnaire focussed on support to *parents* and the primary focus of the professionals in children’s services is on promoting and protecting the welfare of *children*.

**Table 1: The range of agencies providing support to parents**

Organisation or agency	Numbers responding
Community learning difficulty teams	25
Other support services	12
Advocacy services	10
Social services or learning difficulties directorates	5
Children’s organisations	5
National charities	4
Sure Start or Home-Start	4
Health trusts or PCTs	2
Other	6
<b>Total</b>	<b>73</b>

(Note that total responses to different questions vary as not all questions were relevant to all respondents and multiple responses were possible for some questions).

**Table 2: The range of professionals involved in teams providing services to parents with learning difficulties**

<b>Professional</b>	<b>Number of teams</b>
Community learning disability nurse	39
Psychologist	37
Speech and language therapist	30
Occupational therapist	28
Social worker in adult service	27
Support worker	25
Health visitor	23
Advocate	23
Midwife	18
Social worker in children and family/child protection services	17
Solicitor	13
Child protection review officer	11
Day service worker	11
Legal representative	11
Sure Start	10
Family link worker	11
Children's guardian	7
Teacher	6
Residential worker	5
Home-Start worker	4
Psychiatrist	3
Community psychiatric nurse	2
Children and Family Court Advisory and Support Service (CAFCASS)	3
Trainer	2
Other	8

**Table 3: The types of service provided**

<b>Type of service</b>	<b>Number of agencies providing service</b>
Emotional support for parents	60
Skills training for parents	48
At home needs assessment	48
Supporting during judicial proceedings	44
Advice about obtaining benefits	45
Advocacy	44
Support after judicial process	36
In home support	36
Education for parents to be	36
Counselling	32
Help with direct payments	25
Peer support	18
Needs assessment at residential service	14
Day care for children	9
Health needs	5
Legal support during child protection	5

**Table 4: Types of assessment used to assess parents' needs**

Type of assessment	Number of services
Parent Assessment Manual	17
Psychometric testing*	14
Home visits/getting to know the parent	12
Assessments by speech and language therapists	6
Assessments by occupational therapists	5
Community care assessment	5
Joint assessment with children's services	4
IQ test	3

**Table 5: Number of families supported by individual workers**

Number of families supported	Number of respondents
1-5	36
6-10	8
11-15	11
16-20	3
20 plus	3
<b>Total</b>	<b>61</b>

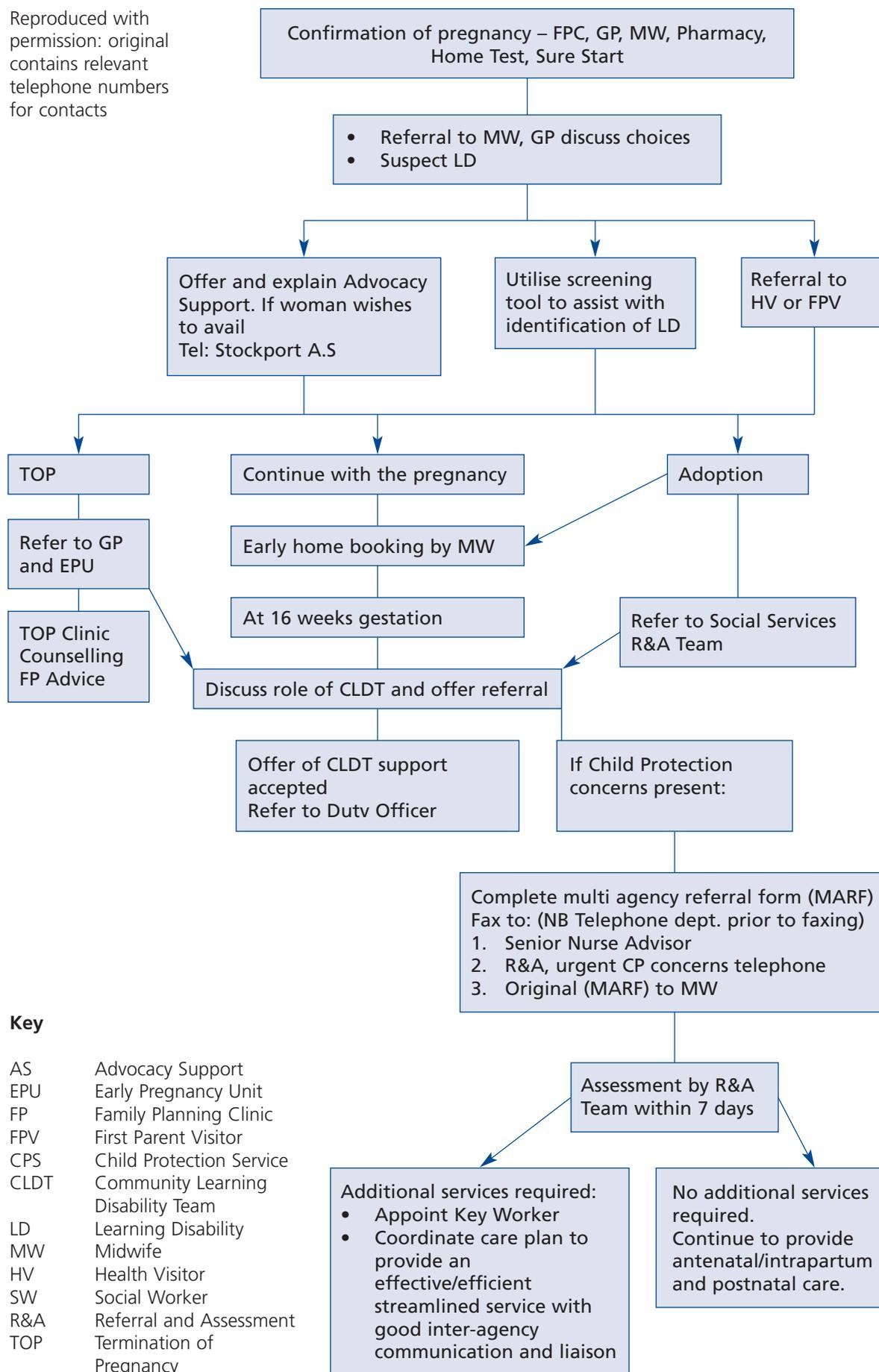
**Table 6: Most frequently cited kinds of training received by workers**

Type of training	Number of workers
No specific training	34
Child protection	12
Communication with people with learning difficulties	8
Parenting Assessment Manual	6
Vulnerable adults training	5
Specific training on parenting by people with learning difficulties	5
The judicial process/courts	4

\*Full details of the various psychometric tests that can be included in assessments are described in McGaw and Newman (2005).

# Appendix 3: Care Pathway for Pregnant Women with a Learning Disability in Stockport

Reproduced with permission: original contains relevant telephone numbers for contacts



## Key

AS	Advocacy Support
EPU	Early Pregnancy Unit
FP	Family Planning Clinic
FPV	First Parent Visitor
CPS	Child Protection Service
CLDT	Community Learning Disability Team
LD	Learning Disability
MW	Midwife
HV	Health Visitor
SW	Social Worker
R&A	Referral and Assessment
TOP	Termination of Pregnancy



An increasing number of adults with learning difficulties are becoming parents. The English White Paper, *Valuing People*, commits the government to providing appropriate support to these parents and their children, as does the Scottish policy document, *The Same as You?*. Yet in around 50% of cases children are removed from their parents and permanently placed outside the family home.

*Finding the Right Support?* was commissioned by the Baring Foundation to map the issues confronting parents and professionals in this complex area and to document positive practice in providing parents with learning difficulties and their children with the 'right support' to stay together as a family.

Beth Tarleton is a research fellow at the Norah Fry Research Centre, University of Bristol, where Joyce Howarth was formerly a researcher. Linda Ward is Professor of Disability and Social Policy at the University of Bristol and Director of the Norah Fry Research Centre ([www.bris.ac.uk/Depts/NorahFry](http://www.bris.ac.uk/Depts/NorahFry)).

Cover design by Karen Gyde. Cover photo posed by models, courtesy of [www.JohnBirdsall.co.uk](http://www.JohnBirdsall.co.uk)

ISBN: 0-9538040-6-2

The Baring Foundation  
60 London Wall  
London EC2M 5TQ

Tel: 0207 767 1348  
Fax: 0207 767 7121

Email: [baring.foundation@uk.ing.com](mailto:baring.foundation@uk.ing.com)  
Website: [www.baringfoundation.org.uk](http://www.baringfoundation.org.uk)

Charity registration number 258583

**This report is free of charge**

**May 2006**

**The Baring Foundation**



**Norah Fry Research Centre**  
University of Bristol