

Finding the right support?

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

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. **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.
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?

(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.

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