



## **Working Together With Parents Network**

Supporting professionals working with  
parents with learning difficulties

### **Parents with learning disabilities—An Introduction**

#### **Introduction**

Parents with a learning disability are likely to be amongst the more marginalised and vulnerable members of society, and may need support from welfare services for a variety of reasons. They might struggle with literacy, everyday practical tasks and abstract concepts such as time, as well as the wide range of social disadvantages common to adults with learning disabilities such as poverty, poor housing and social exclusion (Cleaver and Nicholson, 2007; Horwath, 2007; McConnell and Llewellyn 2002; SCIE 2005).

#### ***What is a learning disability?***

A range of terms can be found in the literature referring to people suffering a level of cognitive limitation or impairment. We do not have the space here to explore all the nuances of the different terms used but outline the 'formal' definition of the commonly used expression 'learning disability' set out by the Department of Health (2001). A learning disability is a:

*'A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development'.* (Department of Health, 2001, page 14)

There is also a far wider group of adults who may be described as having a learning difficulty. These adults do not have a formal diagnosis (because their impairment is milder) and would not generally fit the eligibility criteria for support services in their own right from Learning Disability Services (Department of Education and Skills 2003). However, their needs for services may still be significant. This paper uses the term learning disabilities to include this far wider group of, parents who often struggle with the same issues when parenting but who are not involved with services (Edgerton 2001). As noted, other terms such as intellectual disability and cognitive limitations are found in the literature and these will be used in this paper when referencing publications using these terms. These terms are inter-changeable with the term learning disability. The term intellectual disability is used internationally.

#### ***Parenting by adults with a learning disability***

Little is specifically known about parents with learning disabilities who do not come into contact with Children's Services. There is, however, a substantial literature regarding the barriers adults with learning disabilities face when becoming a parent and with their on-going parenting, the reasons why a larger than expected proportion of children are removed from the care of their families and how support can be provided to parents who have a learning disability. These issues are discussed in sections below.

Parents with learning disabilities often come into contact with services due to concerns regarding the welfare of their children. Studies suggest that these concerns are often in relation to neglect (i.e. maltreatment through omission) rather than deliberate abuse (McConnell and Llewellyn, 2002; Tymchuk, 1992).

Cleaver and Nicholson (2005), in a study of the issues relating to parents with learning difficulties undertaken from a social work perspective, linked the issues of concern to lack of parental education and support services. Cleaver and Nicholson (2005) and others also recognised that when children were removed from parents with learning disabilities, there were also other factors present such as mental health/physical health problems, substance abuse, isolation from friends, poverty and inadequate housing. In addition, some parents with learning disabilities may not have had positive experiences of being parented themselves. A study of the special parenting service in Cornwall, for example, found that three quarters of the parents involved with the service reported abuse and neglect in their own childhoods (McGaw *et al* 2007).

### ***How many parents with learning disabilities are there?***

The most recent figures, from the first national survey of adults with diagnosed learning disabilities in England found that one in 15 of the 2,898 adults interviewed had children (Emerson *et al*, 2005). An extrapolation from these figures indicates that there could be 53,000 parents with learning disabilities in England (Ward 2008). This figure does not include the far larger group of parent who are regarded as having a learning difficulty.

Literature from Europe provides some indicative figures regarding the number of children born to parents with an 'intellectual disability' (international term used). Willems *et al* (2007) estimated that there were 0.6 families with parental LD per 1000 families in the Netherlands while Weiber *et al* (2011) found that 2.12 per 1000 children are born per year to women with learning disabilities in Sweden. Other research has indicated birth rates in a similar range. In Germany, an estimate based on the study by Pixa-Kettner (2008) indicated a prevalence rate of 0.15. Pixa-Kettner compared the findings of the 2008 survey with a previous study in 1998. The new study indicated a 64% rise in parents with intellectual disability compared with the previous survey. Pixa-Kettner argued that the rising number of parents with ID reflected the fact that more people with learning disabilities are now living 'ordinary lives' in the community (Pixa-Kettner 1998, 2008).

### ***How many parents are involved with Children's Services?***

There are no definitive statistics regarding the number of parents with learning disabilities involved with Children's Services. However, a recent study found that 12.5% of the parents involved in Care proceedings had learning difficulties (term used in study) (Masson *et al*. 2008). Similarly, a recent Canadian study found that parental cognitive impairment (term used in study) was noted in 10.1% of sampled cases that were opened for child maltreatment investigation in 2003, and in 27.3% of sampled cases that resulted in child welfare court application (similar to child protection proceedings) (Mc Connell *et al* 2011).

Booth and Booth (2004) found that in one local authority, approximately one sixth of care proceedings involved at least one parent with learning difficulties and in three quarters of these cases the children were removed. Cleaver and Nicholson (2005) found that in less than twenty percent of cases involving parents with learning disabilities the children were permanently removed and that most were fostered rather than being adopted.

In the national survey of adults with learning disabilities mentioned in the last section, Emerson *et al* (2005) found that forty percent of the parents interviewed were not living with their children (although the parents were not asked where their children were living – ie with other family members, with foster carers or if they were older and had moved out).

### ***Children of parents with learning disabilities***

A recent review of the literature focusing on the outcomes for children whose parents have learning disabilities found that:

*'There is no consensus in the findings from studies reviewed about whether having a parent with intellectual disabilities [term used] inevitably results in poor child outcomes. Some studies suggest that these children will be disadvantaged by their parents' low intellectual capacity; others suggest that once other factors are taken into account, such as heightened risk in pregnancy and poor birth outcomes, poverty and troubled parental childhoods, and social isolation and stigma, child development approaches population norms.'* (Collins and Llewellyn 2012 page 80)

This statement is however limited by the fact that most of the studies were undertaken with children under 5 years of age so do not reflect the experiences of older children and young people, or provide information about longer-term outcomes.

Previous reviews such as Mc Connell *et al* (2008) and Feldman (2002) also summarised the literature regarding outcomes for children noting that, although studies had the same limitations in relation to clinical populations and the young age of the children, the research suggests that children of parents labelled with learning disabilities as a group, are at risk of poor developmental outcomes. McConnell *et al* do concur with Collins and Llewellyn in suggesting that the children's outcomes are not, however, directly linked to their parents' learning disability. Rather, it is believed that there is a relationship between children's outcomes and a wide range of factors that impinge on their parent's ability to parent to the best of their ability, such as social isolation and stigma. This is in line with studies by Feldman and colleagues that identified a link between the mother's level of social support and child outcomes (Feldman and Walton-Allen 1997; Feldman *et al* 2002).

These findings suggest that each family's situation should be considered individually, to understand the factors that may be impacting both on the parents' abilities to cope well at any particular stage and on the children's experiences. The children of these families report difficulties such as such as bullying and teasing by their peers as well as social isolation and stigma relating to their parents' learning disability. They also report loving their parents and having secure attachments (Booth and Booth 1998; Faureholm 2010; Perkins *et al* 2002; Ronai 1997). Gustavsson (1997, summarised in Faureholm 2010) reported a positive picture of parenting by a mother with learning disabilities while Faureholme's (2010) report of a ten year longitudinal Danish study following 23 children of parents with learning disabilities found the '*despite tough odds, the children managed fairly well in life* (page 74).' Faureholme observed that the children were '*not victims or passive recipients*' (page 74) but resourceful young people who coped with the barriers they faced and as:

*'Young adults who challenge the view that children of parents with intellectual disabilities are pre-determined to share the same social status as their parents.'* (pages 74-75)

It should be noted that in Denmark, there is provision for families headed by parents with a learning disability to receive continuous and comprehensive support and that the majority of the children attended residential 'after-school' in their teenage years which provided enrichment activities (Faureholm 2010).

### ***Barriers to 'good enough' parenting***

Parents with learning disabilities experience a wide range of barriers which inhibit their ability to parent. The barriers can begin well before a child is even conceived, through the attitudes found in society. People with learning difficulties report being seen as childlike and may face opposition to their desire to parent or dismay at the announcement of a pregnancy. Some parents face the assumption that the pregnancy was a mistake and pressure for an abortion (Booth and Booth 1995; Llewellyn 1994; Mayes *et al* 2006; Sigurjonsdottir and Traustadottir 2000).

Once involved in the parenting process, adults with learning disabilities may face:

#### *Assumptions/stereotypes regarding their abilities*

- Negative expectations about their parenting ability. Parents feel that their learning disability/difficulty is automatically equated with inability to parent and any parenting difficulties are automatically linked to their learning difficulty without considering other environmental or social factors (Tarleton *et al* 2006)

- Assumptions that their capacity to parent can not improve as it is an inherent part of their disability so their child would be best placed with an adoptive family (Booth *et al* 2006; Mc Connell *et al* 2006)
- Negative stereotypes that parents with learning difficulties could never be good enough parents (CHANGE 2005; Cooke 2005)
- Low self esteem and lack of confidence because of previous discrimination and segregation and the on-going scrutiny of their parenting (Tarleton *et al* 2006)

*Lack of parenting knowledge and lack of opportunity to develop skills.*

Adults with learning difficulties:

- are often overlooked as potential babysitters for friends and family,
- do not have easy access to appropriate easy to understand information about parenting and family life and are unable to read the vast array of material available to parents with higher levels of literacy,

*Lack of appropriate support*

- Parents have smaller social support networks (Feldman *et al* 2002; Llewellyn *et al* 1999; Llewellyn and Mc Connell 2002) and may not have good role models with regard to parenting
- There is a lack of clarity and consistency amongst different professionals involved with their family on what constitutes good parenting, each professional offering different advice and adding to their confusion (Tarleton *et al* 2006)
- Use of IQ levels as a proxy for parenting ability without detailed assessment of the individual's abilities and support needs
- Mainstream services that are not equipped to work with parents with learning difficulties (Goodringe 2000; Tarleton *et al* 2006). Cleaver and Nicholson (2005) clearly recognised that workers in Children's Services did not have the experience or the training required to work with parents with learning disabilities. Services are also reported as unable to provide early pro-active and on-going support and as not working in a multi-agency manner to support parents with learning disabilities.

Parents are also reported as being fearful of asking for help with their parenting or of engaging with professionals seeking to safeguard their children's welfare. Parents fear that their child/ren will be removed if they admit to difficulties with their parenting. Many parents with learning difficulties have already had children removed from their care and are grieving for lost children and hostile to the services and workers who removed their child/children from their care. Traustadottir and Bjorg Sigurjonsdottir (2010) suggest that parents' resistance to involvement with services is their way of protecting their family. Many of the issues are also summarised the IASSID Special Interest Research group on Parents and Parenting with Intellectual Disabilities (IASSID 2008).

### **Legislation, Policy and Guidance**

This section provides a brief outline of legislation, policy and guidance relating to work with parents with learning disabilities. It is not intended to be exhaustive but to draw attention to some key provisions, with links to allow you to access relevant documents and websites for more in-depth information.

- Children Act 1989
- Children Act 2004
- NHS and Community Care Act 1990
- Human Rights Act 1998
- Every Child Matters (2003)
- *National Service Framework for Children, Young People and Maternity Services* (2004)
- *Think Family* (2008)
- *Working Together to Safeguard Children* (2010)
- *Valuing People* (2001) and *Valuing People Now: A new three-year strategy for people with learning disabilities* (2009)
- *The English Good Practice Guidance on Working with Parents with a Learning Disability* (DH/DfES 2007) and *Scottish Guidelines for Supporting Parents with Learning Disabilities* (SCLD 2009)

## Legislation

### **Children Act 1989**

A key principle of the Children Act 1989 (CA 1989) is that children should usually be brought up in their own family. This is clearly stated in Section 17 (1):

*It shall be the general duty of every local authority [...]*

- *to safeguard and promote the welfare of children within their area who are in need; and*
- *so far as is consistent with that duty, to promote the upbringing of such children by their families by providing a range and level of services appropriate to those children's needs.*

Section 17 (10) defines a 'child in need' as follows:

*(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part;*

*(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or*

*(c) he is disabled*

Local authorities should support families by offering a range of services appropriate to the child's needs. The Act assumes that services are best delivered working in partnership with parents and emphasises the need to ascertain, as far as is practicable, the wishes and feelings of the parents and also those of the child (considered in light of his/her age and understanding). While there is no specific guidance in the CA 1989 about working with parents with learning disabilities, a number of local authorities have devised inter-agency protocols to facilitate partnership working. An example of such a protocol is Suffolk ACCORD, which sets out the principles to support joint working with disabled parents. The aim of ACCORD is: *"to promote the safety, wellbeing and best outcomes for families where there is a disabled parent, through the **services working effectively together to deliver prompt and co-ordinated responses at all levels and stages**"* (emphasis added).

<http://www.sccpolicies.info/download.php?view.121>

However, while Section 17 CA 1989 indicates that the aim should be to keep children within their own families if possible, this cannot be pursued at all costs. Section 1 of the CA 1989 states that, in court proceedings, the welfare of the child is the paramount consideration; so this must take precedence in all decisions made about the child - and in some cases, the child's welfare needs may conflict with the needs and wishes of the parents. This may be a particular issue when there are child protection concerns, ie when there are grounds to believe that a child is experiencing or is at risk of experiencing significant harm (see notes re Section 47, CA 1989 below).

Section 47 of the CA 1989 outlines the duty of the local authority to investigate where they have reasonable cause to suspect that a child in their area is suffering, or is likely to suffer, significant harm. Literature has clearly shown that parents with learning disabilities, like other parents in this situation, are likely to find it very stressful to be involved in child protection investigations. Parents with learning disabilities may have particular difficulties understanding this complex system and the decision-making processes involved, so extra input may be necessary to ensure that parents can participate as fully as possible. The use of independent advocates has been shown to support parental engagement in this situation (Tarleton 2006; Tarleton 2008).

### **Children Act 2004**

This Act places a duty on all agencies working with children and families to exercise their functions having regard to the need to "safeguard and promote the welfare of children" and broadly enshrines in legislation the five outcomes for all children that were set out in New Labour's *Every Child Matters* initiative (DfES, 2004): being healthy; staying safe; enjoying and achieving; making a positive contribution; and achieving economic well-being.

Section 10 of the CA 2004 addresses the requirement for key agencies (including local authorities, health and police services) to cooperate "to improve well-being", noting:

*(2) The arrangements [for cooperation] are to be made with a view to improving the wellbeing of children in the authority's area so far as relating to-*

*(a) physical and mental health and emotional well-being;*

- (b) protection from harm and neglect;
- (c) education, training and recreation;
- (d) the contribution made by them to society;
- (e) social and economic well-being.

(3) In making arrangements under this section a children's services authority in England **must have regard to the importance of parents and other persons caring for children** in improving the well-being of children. (Emphasis added)

(Similar provision is made for Wales in section 25 of the CA 2004.)

Section 11 places a statutory duty on a number of named agencies to make arrangements to safeguard and promote the welfare of children. The equivalent provision for Wales is found in section 28.

Moving from legislation focused on children and families to law that relate more directly to the support, protection and care needs of (vulnerable) adults:

Certain groups, including people with learning disabilities, are identified as potentially eligible for community care services but there is no specific legislation addressing the needs of people with learning disabilities; however, all disability law could be relevant (Johns, 2009, page 79), along with other provision relating to 'vulnerable adults'. The legal framework for safeguarding 'vulnerable adults' is discussed very fully in a recent guide published by SCIE: *Safeguarding adults at risk of harm: A legal guide for practitioners. Adults' Services SCIE Report 50* (Mandelstam, 2011).

<http://www.scie.org.uk/publications/reports/report50.pdf> (Accessed 17.12.12)

### **NHS and Community Care Act 1990**

This is a key piece of legislation governing social work with disabled adults. It places a duty on local authorities to carry out an assessment of need for people who appear to them to need community care services – this includes older and also disabled people; the local authority then decides whether those needs call for the provision by them of services (Section 47(1)). In coming to a decision, the local authority will have regard to the eligibility criteria that have been specified. The guidelines on eligibility for access to services in England, set out in the national Fair Access to Care Services (FACS) framework (2010) are relevant here (see Brand *et al*, 2010). Adults with learning disabilities who are parents should be provided with support if they are not able to fulfil their parenting responsibilities. Support should be provided so that needs should not worsen or increase through lack of help and 'therefore compromise key aspects of independence, including involvement in..... parenting responsibilities. para 65). A 'critical' level of need includes: 'Vital family and or others social roles and responsibilities cannot or will not be undertaken'; while a 'substantial' level includes: 'the majority of family and other social roles and responsibilities cannot or will not be undertaken' (Department of Health, 2002 paragraph 16, quote in DoH and DES Good Practice Guidance on working with parents with a learning disability, page 52). (The eligibility levels remained the same when the guidance was revised in 2010).

### **Human Rights Act 1998**

In the context of work with parents with learning disabilities, a number of Articles within the European Convention on Human Rights (ECHR) will require consideration. Article 8 is particularly relevant, stating that:

*Everyone has the right to respect for his private and family life, his home, and his correspondence.*  
(Article 8.1)

To be lawful, any interference with this right must be justifiable (in terms specified in section 8.2, ECHR) and proportionate.

### **Policy and Guidance:**

#### **Working Together to Safeguard Children (2013: England)**

This statutory guidance document sets out the responsibilities of organisations and individuals to work together to safeguard and promote the welfare of children and young people, in accordance with the Children Act 1989 and Children Act 2004. As the name suggests, *Working Together* recognises that effective work with

children and families, particularly in the context of child protection, relies on a range of agencies and individuals working well together and provides detailed guidance on the duties, roles and responsibilities of the different professionals involved in making this happen. The current Working Together guidance for England is a much shorter document than its predecessor. For the most part, it has moved away from extensive and detailed instruction about how organisations and individuals should work together in favour of a broad national framework which leaves room for local agencies to develop their own ways of working in order to safeguard and promote the welfare of children. The 2013 Working Together guidance document can be found at <http://www.education.gov.uk/aboutdfe/statutory/g00213160/working-together-to-safeguard-children>.

In Wales, however, the more prescriptive approach to central control of local co-operative working has been retained and is contained in the 2007 guidance document *Safeguarding Children: Working Together under the Children Act 2004*. This document can be found at <http://wales.gov.uk/topics/childrenyoungpeople/publications/safeguardingunder2004act/?lang=en>.

### **Every Child Matters**

*Every Child Matters*, a New Labour initiative, offered a vision of radical improvement in opportunities and outcomes for children, driven by whole-system reform of the delivery of children's services:

In particular, it called for:

- Improved outcomes for children and young people
- A focus on opportunities for all and narrowing gaps
- Support for parents, carers and families
- A shift to prevention, early identification and intervention
- Integrated and personalised services

While parents with learning disabilities are not specifically identified in the context of this initiative, it is important to consider whether and how their support needs can be met within universal services, and to be alert to the possibility that more specialised or targeted services may be needed in addition or as an alternative to mainstream provision.

### **National Service Framework for Children, Young People and Maternity Services (2004: England)**

The NSF identifies the need for maternity services to be *inclusive* and highlights that all women should have access to, and confidence in, the full range of NHS maternity provision. It requires all NHS maternity care providers and Primary Care Trusts to ensure that local maternity services "are inclusive for women with learning and physical disabilities taking into account their communication, equipment and support needs" (2004 page 13).

A similar framework was issued for Wales.

### **Think Family: Improving the life chances of families at risk (Social Exclusion Taskforce 2007)**

Think Family refers to a specific set of reforms developed by the Social Exclusion Taskforce, designed to improve outcomes for children and families with additional needs, based on findings that "families experiencing multiple and inter-generational disadvantage were still achieving poor outcomes despite significant improvements in outcomes across the rest of society" (DCSF, 2009 page 4). The reforms emphasised the need for professionals working in both adults' and children's services to 'think family' – indeed, an early section of the *Think Family* report identified "the crucial contribution of adults' services" (Social Exclusion Task Force, 2008 page 6). Effectively, the message from *Think Family* is that practitioners in adults' services need to have some understanding of an individual's wider needs, including their family circumstances, while children's services workers in turn need to be aware of the adult's (parent/carer) needs and vulnerabilities while maintaining their focus on the child. The Social Exclusion Task Force noted that in a system that 'thinks family', both adults' and children's services would join up around the needs of the family. From the family's perspective, services within this system would:

- Have no 'wrong door'
- Look at the whole family
- Build on family strengths
- Provide support tailored to need

The emphasis on 'joined up' working across adult and children's services should support a holistic understanding of and response to the needs of parents with learning disabilities and their children. However, historically there have been considerable difficulties in establishing effective communication and collaboration between children and family services on the one hand, and adult learning disability services on the other. <https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00685-2009>

As the preceding discussion indicates, there is a wealth of policy directed at children and families. Broadly this has reflected the presumption of the CA 1989 that wherever possible, children should be supported to stay with their families; so if parents need additional support to fulfil their parenting roles, this should be provided by appropriate services working together. Overall, though, there is very little specific reference to parents with learning disability in these 'mainstream' provisions or evidence of a targeted response to acknowledge their particular and potentially on-going (or recurrent) needs for support. However, these have been addressed in a more focused way in the following guidance documents:

### **Valuing People (2001: England)**

#### **Valuing People: A New Strategy for Learning Disability for the 21st Century**

Valuing People is the government's plan (White Paper) for improving the lives of people with learning disabilities, their families and carers. Valuing People recognised that parents are likely to make higher demands on services, the support available to them was 'patchy' (Jigsaw of Services) and called for more effective support for parents with learning disabilities which should be monitored through Learning Disability Partnership Boards. Section 7.40 (page 81) states:

*'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 services 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'.*

### **Valuing People Now: A new three-year strategy for people with learning disabilities (2009)**

*Valuing People Now* recognised the need for parents with learning disabilities to be provided with the support they need. It called for the same level of access to support and information for parents with learning disabilities as all parents as '*evidence suggests that families do not get sufficient access to support, putting families at risk of enforced separation*' (section 3.55 page 73). It also recognised that the importance of advocacy when children are at risk of being removed from their parents' care.

*Valuing People Now* called for earlier support for parents with learning disabilities and for adults and children's services to work together in providing support that fits with the vision set out in '*Think Family*' (2008). The implementation of the *Good Practice Guidance* was also promoted and the commissioning of services jointly funded by Children and Adults services.

### **The English Good Practice Guidance on Working with Parents with a Learning Disability (DH/DfES 2007) and Scottish Guidelines for Supporting Parents with Learning Disabilities (SCLD 2009)**

As the titles indicates, these two guidance documents focus directly on working with parents with a learning disability and start with the assumption that 'people with learning disabilities have the right to be supported in their parenting role, just as their children have a right to live in a safe and supportive environment' (DH/DfES, 2007 page 1). Their aim is 'to help services to improve their support for parents with a learning disability and their children' and to 'increase the chances of the children of parents with a learning disability continuing to live with them in a positive and supportive environment that meets their children's needs' (DH/DfES, 2007 page 4). To that end, both sets of guidance state that services should provide:

- Accessible information and communication
- Coordinated work between the different agencies involved with parents
- Support based on assessments of parents needs and strengths

- Long-term support
- Access to independent advocacy

The themes within the guidance concur with the emerging positive.

### **Positive Practice**

There is no conclusive evidence why some adults with learning difficulties succeed in their role as a parent and others do not, so early identification of possible difficulties is important and an individually tailored response provided.

### **Identification and assessment of need**

Universal services may have a particularly significant role in relation to early identification, assessment and early intervention. Not all adults with learning disabilities are in contact with, or in receipt of services from, the local authority so 'mainstream' services may be best placed to identify parents or prospective parents who may have learning disabilities, and who may need additional support.

The CAF may be appropriate here and provide a good basis for multi-professional engagement with the family. Use of the CAF is a voluntary process that requires the agreement of the parent(s). It can allow a positive assessment to be undertaken to build an understanding of the strengths of each parent (or prospective parent, if identified during the ante-natal period) in relation to the parenting and care of each child in the family, and also to identify areas where there may be concerns. The assessment and subsequent planning process depends on good information sharing between the different professionals who are, or may usefully become involved with the family.

It should be noted that adult social care services have a responsibility to check whether a person who is referred for community care services has parenting responsibilities for a child under 18. Then, if appropriate, coordinated work with children's services should be undertaken to ensure the fullest assessment of the family's needs. Specialist assessment, involving adult learning disability and health services input, may be required. The *Parenting Assessment Manual* (PAM) (McGaw, 1998 –first edition- offers an approach that is specifically geared towards the assessment of parents with learning disabilities and can be used in coordination with the CAF (DfES 2006) and the *Framework for the Assessment of Children in Need and their Families* (Department of Education and Employment and the Home Office, 2000).

Where a learning disability is identified or suspected, it should not be assumed that this automatically explains any or all difficulties that the parent experiences. Assessment should consider whether and to what extent, other factors may be impacting on parenting in each particular case – for example, parental ill-health (physical or mental), substance misuse, or domestic violence. The effects of living in poverty, in poor housing, and perhaps experiencing harassment or discrimination should also be considered (as indicated by the recognition of the importance of social and environmental factors in the CAF and *Assessment Framework* and their impact on parenting capacity).

### **Family support**

Family support may be provided through the CAF process or following referral, to children's social care services, under the auspices of s17 of the Children Act 1989. Positive or facilitative factors reported consistently in the literature include:

- A positive informal support network
- Competence-building support which helps parents to learn and achieve for themselves
- That parents are not overcoming personal traumas

The literature clearly points towards the importance of social support for parents with learning disabilities and it is suggested that this support may be more important factor in parenting success than whether parents have a learning difficulty (Feldman *et al* 2002; Kroese, *et al* 2002). McGaw and Newman (2005) highlighted the importance of family ties while the survey of adults with learning difficulties (Emerson *et al* 2005) indicated that 9 out of 10 mothers who were living with relatives had their children with them in contrast to 4 out of 10 mothers who lived in their own households.

Successful support for parents with learning difficulties has been found to include:

- The provision of easy information and adapted resources for parents
- Advocacy and self-advocacy support so that parents can speak up for themselves
- Parenting assessments that highlight the parents' skills as well as areas in which improvement is required.
- Interventions that build on parents' strengths and promote children's resilience while modelling good practice. These interventions should be provided in the parents' home using the actual equipment the parent will use.
- Skills teaching which is individually tailored around interesting, relevant topics in the home which is systematic, practical/concrete (rather than abstract) and visual
- Preventative on-going support to parents that builds on their existing skills and abilities, praises their successes. Support should be co-ordinated by a key worker and provided by as few workers as possible.
- Helping parents overcome the wider issues in their lives such as debt, poor housing and harassment
- Support for women and men experiencing violent relationships
- Support for fathers (whose needs have generally been overlooked)

(Budd and Greenspan 1985; CHANGE 2005; McGaw and Newman 2005; Tarleton *et al* 2006; Tymchuck 1992).

### **Child protection**

In some cases, provision of family support services will not be sufficient to safeguard children's well-being and action under s47 of the CA 1989 will be required. While it is clear that the priority must be to ensure the children's safety, professional practice with families going through the challenging and often painful process of a child protection investigation can still draw on much of the good practice guidance noted above. In particular, it is important that parents have access to information in formats that they can understand, time (where possible) to assimilate and respond to information about their case, and support – ideally through an independent advocate – to present their views. In the potentially more fraught atmosphere generated by child protection concerns, and the need for rapid decision-making, it can be harder to make sure that parents' voices are heard.

Advocacy may also be particularly significant if care proceedings are being considered. There are a number of information booklets for parents with learning disabilities which explain the Child Protection System (see easy information for parents below).

### ***Example of positive practice***

#### **Valuing Parents Support Service (VPSS)**

VPSS is a jointly funded venture between Adults' and Children's Services. It aims to provide holistic assessment, intervention and support to parents with learning disabilities with children under eight years of age while also identifying 'high risk' families where children should not be cared for by their parents. The VPSS team strives to implement the Good Practice Guidance on Working with Parents with Learning Disabilities (DH and DfES 2007) and the practical strategies described in Tarleton *et al.* (2006). It also utilised a 'Think Family'

approach (Social Exclusion Taskforce 2007). The team aimed to provide intensive support and training to help parents care for their children appropriately and engage with Children's Services.

At the time of the evaluation from which this example has been developed (Tarleton *et al* 2011) the team was working with families already involved with Children's services. The service aimed in the longer term to provide preventative support to parents with learning disabilities in order that engagement with Children's services would not be necessary.

The support provided by VPSS included supporting parents with everyday tasks such as shopping, paying bills, household organisation, safety and cleanliness as well as specific teaching/role modelling of parenting skills. The team facilitated parents to access mainstream parenting groups and engage with issues that impacted on their ability to parent. These included poor housing, domestic violence and the grief of having previous children removed. VPSS either directly supported them or enabled parents to access specialist services such as the Freedom Project (Domestic Violence). VPSS also provided advocacy support to parents; team members helped parents to understand reports and accompanied them to meetings and court. If children had been removed from their parents' care, team members supported them to move on with their lives and when, appropriate, to remain in contact with their children through supported contact or the letter box process (keeping in contact with an adopted child by post).

The workers at VPSS were from a range of different backgrounds including learning disabilities, child protection, youth work, family support. They worked with parents in a wide range of ways. They:

- Built relationships with parents based on trust and respect. Parents were allocated specific workers who communicated regularly with each other
- Worked in partnership with parents at their pace.
- Used easy to understand materials to enhance parental understanding.
- Enabled parents to access groups provided by Children's services and in the local community
- Supported parents to engage with other services concerned with the welfare of their children
- Engaged in interdisciplinary working where they were respected for their professionalism and due respect for the welfare of the children. Strategies that supported this included; on-going communication with all the other professionals involved with the family, understanding and respect of different professional roles and developing shared clarity around the aims of the assessment and support.

VPSS was regarded as 'vital' to Child Protection plans which a number of child protection workers noted they had 'discharged' early as they were confident in the service's ability to monitor and provide on-going support to families. A Children's worker summarised their role:

'Planning the service [to parents], developing relationships with service users, gaining trust and confidence in the service, assessing need using expert knowledge, promoting choice and independence without compromising risk to selves or children, contributing to decision-making, liaising with other agencies, implementing the support plan, matching support worker and family and developing specialist services/activities'. (Tarleton *et al* 2011 page 22)

The evaluation showed, using a Matching Needs and Services Audit, that children whose parents were provided with support from VPSS had better outcomes than a control group of children from the co-located assessment services.

Tarleton and Porter (2013) discuss the impact of the service on one mother engaged with the VPSS and in consequence a wide range of other support services:

*'One mother was who was pregnant with her eighth child - having had the previous seven removed - provides an insight into the level of issues facing parents and the support provided by the service. This mother had previously had issues with drink, drugs and domestic violence. She spoke of her grief regarding her previous children and exactly where she had been planning to 'jump off the [name] bridge'. She also spoke of her joy at being supported by the service and the concern, commitment and honesty shown by 'her' worker. She was now willing to go to a mother and baby foster placement for assessment when her eighth baby would be born in a few weeks time. Her proposed foster placement was going to be in a new area, away from previous negative influences. She reported feeling better equipped to make sound decisions as a result of her raised self esteem, relationship counselling and anger management classes which had been organised by VPSS' (page 241).*

*Examples of other positive development in the UK supporting mothers with learning disabilities in Shared Lives placements (where the mother and baby reside with a carer), the provision of 24 hour support in the home and clear agreements between Adults and Children's services regarding how support will be provided for parents with learning disabilities through Joint protocols (<http://www.smhp.nhs.uk/Information/ACCORD.aspx>). A recent study also reported on the positive support provided by Duolas during birth (McCarry, Kroese and Cox undated).*

Finding the Right Support (Tarleton, Ward and Howarth 2006) summarised the various ways that positive practice was developing in the UK (<http://www.bristol.ac.uk/wtwpn/resources/right-support.pdf>). The Healthy start network in Australia (<http://www.healthystart.net.au/>) provides a wide range of resources for positive practice. Aunos *et al* (2010) also report on a specialist service provided in Canada. The Working Together with Parent Network has also published a set of 6 Stories of Positive Practice (2009) <http://www.bristol.ac.uk/wtwpn/resources/success-stories/>.

### **User Perspective**

#### **Maggi, David and Anne**

Maggi and David had been married for three years and, in Maggi's words, 'unusually for where we live we didn't have a child until after we were married'. Their daughter, Anne, is 19 months old, well advanced in her language development (according to their health visitor) and loves any kind of loud musical toy, wires and keys. Maggi and David moved into their new house two days before their daughter was born. They have a 'loopy' dog called Louise. The couple are both mainly at home with their daughter.

Maggi and David are involved with KeyRing, a housing support organisation for people with learning disabilities. Their supporter at KeyRing was 'absolutely brilliant'. 'When we told her we were pregnant, she asked 'if we wanted any help.' As they didn't have a social worker at the time, the Keyring worker supported them to ask for a social worker (which was a long wait), helped them apply for the 'maternity grant' and put them in touch with Flying Start. (A Welsh Assembly Government project providing antenatal, health visiting and other support to families in the most disadvantaged areas of Wales). The KeyRing supporter continued to believe in them and ensure that they were fully informed on what was expected of them, why there were concerns about how things were going with the baby and how to overcome these.

Maggi and David were also supported by workers from Flying Start during the pregnancy, and an antenatal package of care was planned. However, the early arrival of Anne meant this didn't happen: Maggi had pre-eclampsia during pregnancy and had Anne a month early, weighing just five pounds and two ounces. After the baby was born, Maggi and Anne's discharge from hospital was delayed, at KeyRing's request, while Maggi and David were assessed on their ability to care for her appropriately.

Maggi and David were shocked by the extremely negative attitudes of some of the professionals they came into contact with and the number of 'hoops to go through'. They report being told by one social worker that they 'should have got rid of the baby' and that because they have learning disabilities, their daughter will have too.

Maggi and David have had excellent support from their midwife at the maternity hospital, then from the Flying Start health visitor, as well as from KeyRing and from their large extended family. Maggi is one of six children; David is one of four sons. Anne is the first grandchild on David's side and her paternal grandparents are besotted with her.

Maggi describes the hospital midwife as a 'superstar'. She supported them with Anne's feeding, and then liaised with their 'wonderful health visitor from Flying Start', when they brought Anne home from hospital at ten days old. When they came home from hospital, they were visited by professionals from the Flying Start team twice daily, seven days a week for the first three weeks. These visits spanned both day and evenings, to ensure that support was available when needed.

Their supporter from KeyRing and the Flying Start family support worker encouraged the housing department to get the family a house quicker than usual and in the location they needed, so they could support David's parents, who have medical problems.

Their Flying Start health visitor helped a number of times with weaning Anne, taking them through from the premature baby milk, to standard baby milk, and then on to solid food. Maggi feels confident to ring her health visitor whenever she has a question or concern. On the day of the interview for this story, Anne has a virus and Maggi has been in contact with her GP, the Flying Start health visitor and her mum for advice.

The Flying Start team gave Maggi breastfeeding and other parenting advice using visual aids, pictures, posters and a book to enable the family to establish good routines and ensure home safety. Maggi describes their support as 'ace' and 'worth their weight in gold'. Maggi and David are still involved with Flying Start, and attend a parenting group, which provides contact with other parents, advice and trips out in the summer holidays. A new package of care has just been initiated, because their needs for support fluctuate as Anne's developmental needs change. The current involvement is around supporting age-appropriate play for six weeks, in the home. However, regular telephone calls and support within the group will continue to provide into the future.

#### **Adapted from one of the stories of Positive Practice WTPN 2009**

<http://www.bristol.ac.uk/wtpn/resources/success-stories/>

#### **Research Articles**

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008) Parents labelled with Intellectual Disability: Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 2008, 21, 296–307

Ward, L. & Tarleton, B. 2007, 'Sinking or Swimming? Supporting Parents with Learning Disabilities and their Children' *Learning Disability Review*, 12 (2), pp22-32.

See reference list below for articles on key aspects of research.

#### **Publications and reports**

Aldridge, J and Wates, M. 2005 'Young carers and disabled parents: Moving the debate on' in Newman, T and Wates, M. (eds) *Disabled parents and their children: Building a better future – A discussion document*, Ilford: Barnardo's.

Booth, T. and Booth, W. 2003 *Self-advocacy and supported learning for mothers with learning difficulties*. [www.supported-parenting.com/projects/SLPpaper Final copy.pdf](http://www.supported-parenting.com/projects/SLPpaper%20Final%20copy.pdf)

Booth, T. and Booth, W. 2004. *Parents with learning difficulties, child protection and the courts*. [www.supported-parenting.com/projects/NuffieldReport.pdf](http://www.supported-parenting.com/projects/NuffieldReport.pdf)

CHANGE (2005) *Report of National Gathering of Parents with Learning Disabilities*, Leeds, CHANGE

Cleaver, H. and Nicholson, D. (2008) *Parental learning disability and children's needs: family experiences and effective practice*, Jessica Kingsley

Lindley, B & Richards, M., 2002 *Protocol on Advice and Advocacy for Parents (Child Protection)*, Cambridge, Centre for Family Research, University of Cambridge

SCIE (2005) [Helping parents with learning disabilities in their role as parents](#). SCIE research briefing 14. London, SCIE.

Tarleton B, Ward L and Howarth J (2006) [Finding the Right Support? A review of issues and positive practice to support parents with learning difficulties and their children](#). London, Baring Foundation <http://www.bristol.ac.uk/wtwpn/resources/right-support.pdf>

Working Together with Parent Network (2009) *Supporting parents with learning disabilities and difficulties – Stories of positive practice*. Bristol, Norah Fry Research Centre. <http://www.bristol.ac.uk/wtwpn/resources/success-stories/>

### **Good Practice Guidance on Working with Parents with Learning Disabilities**

Guidance produced by the Department of Health and the Department of Education regarding supporting parents with learning disabilities. The 67 page guide for commissioners and staff working in children's and adult's social services to work together to support parents with a learning disability.

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075119](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119)

There is an easy read version of the above guidance.

<http://www.changepeople.co.uk/freebies-download.php?id=9>

### **Books**

Booth, T. & Booth, W. (1994) [Parenting Under Pressure: Mothers and fathers with learning difficulties](#). Milton Keynes, Open University Press.

Booth, T. & Booth, W. (1997). *Exceptional childhoods, unexceptional children*, London, Family Policy Studies Centre.

Booth, W. & Booth, T. (1998) *Advocacy for parents with learning difficulties*. Brighton, Pavilion Publishing.

Booth, T. & Booth, W. (1998) *Growing up with Parents who have Learning Difficulties*. London, Routledge.

Cleaver, H. and Nicholson, D. (2008) *Parental learning disability and children's needs: family experiences and effective practice*, Jessica Kingsley

Joint Committee on Human Rights (2008) *A life like any other? Human rights of adults with learning disabilities*. London: The Stationery Office (or download from [www.parliament.uk/jchr](http://www.parliament.uk/jchr) or [www.right-support.org.uk](http://www.right-support.org.uk))

Olsen, R. and Tyers, H. (2004) *Think Parent: Supporting disabled adults as parents*, London, National Family and Parenting Institute. Findings can be seen at: <http://www.irf.org.uk/knowledge/findings/socialcare/n34.asp>

McGaw, S. & Newman, T. (2005) *What works for parents with learning disabilities?* Ilford, Barnardo's.

## **Organisations and service providers**

### **Action for Advocacy**

Action for Advocacy (A4A) is the central point of information on independent advocacy. Service include find an advocate search. <http://www.actionforadvocacy.org.uk/>

### **Change**

CHANGE is a leading national human rights organisation led by Disabled People. Change works for the human rights and inclusion of all people with learning disabilities. Change campaigns for the rights of parents with learning disabilities, produces easy to read information and provides training. See below for easy to read resources.

### **Disability Rights UK**

Disability Rights UK works to create a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

Disability Rights UK is led, run and controlled by disabled people, with disabled people making up at least three-quarters of its board members.

Disability Rights UK focuses on:

- Breaking the link between disability and poverty
- Mobilising disabled people's leadership and control – in our own lives, our organisations and society
- Making independent living a reality
- Putting disability equality and human rights into practice across society

<http://www.disabilityrightsuk.org/about.htm>

### **Elfrida Parents project**

The Elfrida Parents helps parents with learning difficulties get the right support and to support each other. Support includes one to one and group support, advocacy and parenting courses.

<http://www.elfrida.com/parents.html>

### **Disability, Pregnancy and Parenthood international (DPPi)**

DPPi provides an information service to help disabled parents and professionals with enquiries. For details of current and forthcoming information sheets on a range of practical issues ring the helpline or see the website. Back copies of Disability, Pregnancy and Parenthood International Journal can be seen on website. DPPi has a reference collection of information and resources that can be seen by arrangement. [www.dppi.org.uk](http://www.dppi.org.uk)

### **Family Action**

Family Action's Valuing Families service supports parents with learning disabilities and their children. Based on the successful Building Bridges model, support is provided on an outreach basis, working with families in their

own homes. Building Bridges Model is a cost-effective and multi-agency approach, adding value to adult and children's services, health officials, education and social care.

<http://www.family-action.org.uk/section.aspx?id=782>

**Family Rights Group** Family Rights Group is the charity in England and Wales that advises families whose children are involved with or need children's services because of welfare needs or concerns.

We promote policies and practices, including [family group conferences](#) and a support framework for children living with [family and friends carers](#), so that:

- children and their families have a greater say and influence over decisions about their lives and services they need or use
- more children are raised safely and securely within their families.

The voice of children and their families, who have experience of or need children's social care services, governs out work.

<http://www.frg.org.uk/about-us>

### **Healthy start**

Healthy Start is a Australian national capacity building strategy which aims to improve health and wellbeing outcomes for children whose parents have learning difficulties. <http://www.healthystart.net.au/home>

### **London Network of Parents with Learning Difficulties**

This network brings parents with learning difficulties together for mutual support while offering advice and training to service providers. It has produced the Parenting Toolkit –see below.

<http://www.londonparents.net/>

### **Learning Disability Wales**

Partner organisation in the Working Together with Parents Network that co-ordinates the Network in Wales. The WTPN (see below) is a network for professionals working with parents with learning difficulties.

[http://www.learningdisabilitywales.org.uk/parents\\_network.php](http://www.learningdisabilitywales.org.uk/parents_network.php)

### **SCLD**

Partner organisation in the Working Together with Parents Network that co-ordinates the Network in Wales. The WTPN (see below) is a network for professionals working with parents with learning difficulties.

<http://www.sclد.org.uk/sclد-projects/working-with-parents>

### **Information for parents with learning disabilities**

**Change** (see above) have produced a wide range of resources specifically for parents with learning disabilities and a wide range of resources regarding everyday living. These include:

Books on parenting: My Pregnancy: My Choice, You and your little Baby and You and Your Little Child

Books on sex and relationships: friends and relationships, sex and relationships, sexual abuse, safe sex and contraception.

Change also have picture banks, available to purchase on My Pregnancy, You and Your Baby, You and Your Little Child as well as picture banks focusing on Independent living and Housing.

There are picture bundles (for you to use to make your own easy information) on relationships, sex, abuse (sexual, emotional, bullying), healthy eating and healthy foods. Pregnancy, mental health and supporting parents with learning disabilities.

There are training cards on Child Protection, Assessment, Working Together, Communication, Support and After Adoption.

All of these resources are available from the Change on-line shop <http://www.changepeople.co.uk/shop.php>.

Change offers training 'Parents Training for Change' contact  
[http://www.changepeople.co.uk/uploaded/General\\_info\\_CHANGE\\_training.pdf](http://www.changepeople.co.uk/uploaded/General_info_CHANGE_training.pdf)

### **Pregnancy and Childbirth**

Easy to read book on Pregnancy and childbirth.

<http://www.bild.org.uk/our-services/books/health-and-well-being/pregnancy-and-childbirth/>

Also available from Bild, books on sex, using medicine safely and looking after your teeth.

<http://www.bild.org.uk/our-services/books/health-and-well-being/>

### **Information about child protection**

#### **Parents booklet**

This is a **free** book that tells parents what might happen if Children's services feel their child is at risk of harm.

This booklet was written with parents with learning disabilities.

<http://www.voiceability.org/images/uploads/Parents%20brochure%202011.pdf>

#### **Understanding the Family Court System**

A 23 page booklet written by parents with learning disabilities to help parents with learning disabilities understand what happens at the Family Court where decisions are made about their children.

<http://www.dorsetadvocacy.co.uk/span/ufcs.htm>

#### **The court and your child: when social workers get involved**

A booklet with easy words and pictures written by lawyers about what happens during Child Protection Proceedings. Available from CHANGE (see above) and downloadable from

<http://www.bristol.ac.uk/norahfry/right-support/download/socialworkers.pdf>

### **Raising Children website**

The complete Australian resource for parenting newborns to teens

Including videos on breast feeding, game, step by step pictorial and easy text guidance on a wide variety of parenting tasks.

[http://raisingchildren.net.au/articles/pip\\_burns\\_first\\_aid.html/context/1221](http://raisingchildren.net.au/articles/pip_burns_first_aid.html/context/1221)

### **Accident Prevention**

The Child Accident prevention Trust has produced a range of resources for all parents. The resources are colourful and use lots of picture and would be suitable for sharing with parents with learning difficulties.

Information is available in relation to the child's age or the type of risk.

<http://www.capt.org.uk/shop/parents-packs>

## **Making information accessible**

### **CHANGE**

The Words to Pictures Team is a team of people with learning disabilities who work with an illustrator to produce information in an easy read format using easy words and pictures. The Team produces CD Roms (picture banks) of hundreds of pictures for organisations working with people with learning disabilities. Illustrators in CHANGE can also draw additional pictures as and when necessary.

CHANGE turns other organisations' documents, posters, flyers, leaflets, Annual Reports into an accessible format and people with learning disabilities provide training around how to make information accessible and how to use the Picture Bank CD Roms.

For more information contact:

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

[info@changepeople.co.uk](mailto:info@changepeople.co.uk) Tel. 0113 243 0202; Fax. 0113 242 0220.

[www.changepeople.co.uk](http://www.changepeople.co.uk)

### **Mencap**

Mencap's Accessibility Unit publishes a guide on writing accessible documents: 'Am I making myself clear?'

[www.mencap.org.uk/download/making\\_myself\\_clear.pdf](http://www.mencap.org.uk/download/making_myself_clear.pdf)

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

Tel. 020 7696 5551

[accessibility@mencap.org.uk](mailto:accessibility@mencap.org.uk)

[www.mencap.org.uk/html/accessibility/accessibility\\_services.asp](http://www.mencap.org.uk/html/accessibility/accessibility_services.asp)

### **Norah Fry Research Centre Plain Facts team**

Plain Facts is a magazine for people with learning disabilities about research findings. The Plain Facts team also take on other easy read information projects, for example an easy read version of a report on involving people with learning disabilities in their medical care.

Contact: Victoria Mason [mhvam@bris.ac.uk](mailto:mhvam@bris.ac.uk)

## **Projects**

### **Healthy start**

The Australian national strategy for supporting parents with learning disabilities. Information is provided on the 'basics' ie myths and assumptions regarding parents with learning disabilities, how to tailor services, practical tools and research evidence.

<http://www.healthystart.net.au/>

### **Parent Advocate Network**

The Parents Advocate Network was set up in early 2012 to link up advocates supporting parents with learning disabilities or mental health issues. The bi monthly meetings anyone working as an Advocate with parents with Learning Disabilities, or mental health issues to join. This enables them to network with advocacy agencies from across Wales. They can then support each other with hints and tips on problem cases, discuss research, new projects, training ideas etc, as well as sharing best practice. The network is purely for advocates, we do not bring service users to these meetings, so people can speak freely about their worries or concerns about their roles.

They currently have members in the following counties; Pembrokeshire, Ceredigion, Powys, Caerphilly, Bridgend, Cardiff, Newport, Vale of Glamorgan, Torfaen and Monmouth. It is fully supported by Learning Disability Wales.

Further information, dates of meetings etc, can be obtained from the co-ordinator, Mrs Susi de Lacey, Parent Advocate at Carmarthenshire People First on 07805629881 or by emailing [susicpf@yahoo.co.uk](mailto:susicpf@yahoo.co.uk)

### **Working together with parents with Network**

The network aims to spread positive practice and to promote policy change, so that parents with learning disabilities and their children can get better support. The site contains information and resources for professionals, links to other organisations and societies and information for parents with learning difficulties.

<http://www.bristol.ac.uk/wtwpn/>

### **Professional tools**

#### **Enabling Parenting with Support – Effective working with parents with learning disabilities.**

This training pack will enable managers and trainers to ensure staff have the knowledge and skills to provide parents with learning disabilities the best support available, and that these parents are equipped with the skills they need to protect their children and to give them the best possible start in life. The pack is designed to meet the training needs of a range of staff by covering the available evidence base, taking into account the perspectives of parents with learning disabilities and professionals, and by complying with current frameworks for working with families. Using a range of effective learning techniques, it aims to directly enhance the skills of staff who work with parents with learning disabilities in a number of key areas including assessment, communication and teaching parenting skills.

<http://www.pavpub.com/p-533-enabling-parenting-with-support.aspx>

#### **Health and Wellness Program: A Parenting Curriculum for families at risk**

This parent education program helps professionals support teen parents and parents with learning problems, such as intellectual disabilities, learning disabilities, or mental illness. It contains processes and strategies validated over the past 30 years. The program has three components: a program manual, 15 parent booklets, and supplemental resources. The manual includes information on assessing parents' current skills and outlines content to cover in parent education sessions. The parent booklets will be available on our web site or on a CD-ROM for parent educators to print and give to parents for use at home. These illustrated booklets are easy to read. The supplemental resources will also be available on the web site/CD-ROM. They include background information on the program's validation study and a review of research about mothers with cognitive impairments.

<http://www.amazon.co.uk/Health-Wellness-Program-Parenting-Curriculum/dp/1557668175>

#### **Learning curves - The Assessment of Parents with a Learning Disability**

A Manual for practitioners prepared by Penny Morgan and Andy Goff for the Norfolk Safeguarding Board. The authors have collaborated to produce a range of materials designed to

support those involved in the assessment of families where one or both parents have a Learning Disability. Although it is aimed, principally, towards Social Workers required to complete family Assessments, it will also be of interest to other professionals working in the area, as well as managers.

<http://www.nscb.norfolk.gov.uk/documents/LearningCurves.pdf>

#### **Parent Assessment Manual**

The current edition PAMS 3.0 has been developed to present information within a format that interfaces well within the Framework for the Assessment of Children in Need and their Families (2000) and the Common Assessment Framework (DfES, 2006). PAMS 3.0 can be used as a Screening Tool or as a Comprehensive Specialist Assessment. PAMS 3.0 simplifies the measurement of parental capacity and automatically

consolidates the assessment data into template reports to assist the assessor with their report writing.  
<http://www.pamsweb.co.uk/index.html>

### **Parenting toolkit**

This toolkit developed by the London Network of parents with learning Difficulties is 'to help services meet our needs as parents with learning difficulties'.

<http://www.londonparents.net/gettingtoolkit.html>

### **Positive Parenting: Supporting Parents with Learning Disabilities**

This audio CD, produced by Research in Practice, looks at the skills, approaches and research information needed to support this group of families. It focuses on the support that is needed for parents with learning disabilities to be the best parents they can and to make sure that their children do well in their care. It explores the challenges many of these parents face and the ways in which professionals can work alongside parents to ensure good outcomes for the whole family. In particular it highlights the need for adult and children's services to work together.

The CD contains up to date analysis, research and recommended good practice from experts, researchers and policy-makers. It also includes the knowledge and reflections of parents themselves on what they need to provide the best possible parenting for their children.

Available from Research in Practice as a CD and as MP3 download

<http://www.rip.org.uk/publications/audio-series-pub>

### **Pregnancy support pack**

This pack provides information uses a combination of symbols, photographs and easy words to convey all of the information that should be provided to mothers during pregnancy and early post natal period. All of the information can be printed from the CD. Some of the documents are editable so that they can be personalised for mothers.

[http://www.nhsfife.scot.nhs.uk/easyread/findresources\\_cdrom.aspx](http://www.nhsfife.scot.nhs.uk/easyread/findresources_cdrom.aspx)

Contact: If you are interested in receiving a copy of the CD-ROM, please contact Angela Howie, [angelahowie@nhs.net](mailto:angelahowie@nhs.net) or call 01383 565210.

### **Suffolk Accord**

A detailed example of an Interagency protocol for supporting disabled parents.

<http://www.sccpolicies.info/download.php?view.121>

See also the section on information for parents with learning disabilities. All of these resources can be used by professionals to share information with parents. The picture banks can use used to develop individualised information for parents.

### **Journals**

[British Journal of Social Work](#)

Published for the British Association of Social Workers. It covers every aspect of social work, with papers reporting research, discussing practice, and examining principles and theories. It is read by social work educators, researchers, practitioners and managers who wish to keep up to date with theoretical and empirical developments in the field.

[British Journal of Learning Disabilities](#)

[Blackwell Publishing](#)

This is an international peer-reviewed journal with a multidisciplinary approach. The focus is on practical issues, with current debates and research reports. Its readers and authors are academics, practitioners, and others interested in learning disability from a personal or professional perspective. The aim of is to promote better lifestyles and high quality services for adults and children with intellectual disabilities worldwide.

#### [Disability, Pregnancy And Parenthood International \(DPPI\)](#)

The journal shares information and experience on all aspects of parenting with a disability in the UK and overseas.

#### [Journal of Intellectual Disabilities](#)

##### [Sage](#)

This journal provides a medium for the exchange of best practice, knowledge and research between academic and professional disciplines from education, social and health settings to bring about advancement of services for people with intellectual disabilities.

#### **References**

- Bradley, R., Toft, S. & Collins, G. (2000) Parenting assessments. *Learning Disability Practice*, 2, 5, 9-11.
- Brand, D., Green, L. & Statham, D. (2010) *Facts about FACS 2010: A guide to Fair Access to Care Services*. Adult Services SCIE Guide 33. London, SCIE.
- Budd, K. & Greenspan, S. (1985) Parameters of successful and unsuccessful interventions with parents who are mentally retarded. *Mental Retardation* 23, 289-273.
- Booth, T. & Booth, W. (1998) *Advocacy for parents with learning difficulties: developing advocacy support*, York, Joseph Rowntree Foundation.
- Booth, T. & Booth, W. (1995) Unto us a child is born: The trials and rewards of parenthood for people with learning difficulties. *Australia and New Zealand Journal of Developmental Disabilities* 20, 25-39.

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, [www.supported-parenting.com/projects/NuffieldReport.pdf](http://www.supported-parenting.com/projects/NuffieldReport.pdf).

Booth, T. Booth, W. and McConnell, D. (2005) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Intellectual Disability Research* 18, 7-17.

Booth T. Booth, W and Mc Connell, D. (2005) Care proceedings and parents with learning difficulties: Comparative prevalence and outcomes in an English and Australian Court Sample. *Child and Family Social Work* 10, 353-360.

Booth, T. Booth, W. & Mc Connell, D. (2006) Temporal discrimination and parents with learning difficulties in the child protection system. *British Journal of Social Work* 36 (6) 997-1015.

CHANGE (2005) *Report of national gathering of parents with learning disabilities*. Leeds, CHANGE.

Cleaver, H. & Nicholson, D. (2008) *Parental learning disability and children's needs: family experiences and effective practice*. London, Jessica Kingsley.

Collings, S & Llewellyn, G. (2012) Children of parents with intellectual disability: Facing Poor Outcomes or Fairing okay? *Journal of Intellectual and Developmental Disabilities* 37, 1, 65-82.

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

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

Department of Education and Employment and the Home Office (2000) *Framework for the assessment of children in need and their families*. London, The Stationery Office.

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st Century*. London: The Stationery Office.

Department of Health (2009) *Valuing People Now*. London: The Stationery Office.

Department of Health and Department of Education (2007) *Good practice guidance on working with parents with a learning disability*. London, The Stationery office.

Department of Health (2010) Fair access to care services: Practice guidance, London: Department of Health. [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113154](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154)

Department for Education and Skills (2006) *Common assessment framework*. London, Department for Education and Skills.

Edgerton, R. B. (2001) The Hidden majority of individuals with mental retardation and developmental disabilities. In *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations* (eds A. J. Tymchuck, C. K. Lakin and R Luckasson), p 3- 19/ Paul H Brookes, Baltimore

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

Faureholm, J. (2010) Children and their Life Experiences. In *Parents with intellectual disabilities, past, present and future* Eds G. Llewellyn, Traustadottir R., McConnell C. and Sigurjonsdottir H. B. (2010) Wiley Blackwell, West Sussex.

Feldman, M. A. and Walton-Allen N. (1997) Effects of maternal retardation and poverty on intellectual, academic, and behavioural status of school aged children. *American Journal on Mental Retardation* 101, 352-364.

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, 314-323.

Goodringe, S. (2000) *A Jigsaw of services: Inspection of services to support disabled adults in their parenting role*. London, Department of Health.

Horwath, J. (2007) *Child Neglect: identification and assessment*, Basingstoke, Palgrave Macmillan.

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008) Parents labelled with Intellectual Disability: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21, 296-307

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, 324-340.

Llewellyn, G. (1994), *Intellectual Disability and Parenting: A shared experience*. PhD thesis. University of Sydney, Sydney.

Llewellyn, G. & Mc Connell, D. (2002) Mothers with intellectual disabilities and their support networks. *Journal of Intellectual Disability Research* 46, 17-34.

Llewellyn, G., Mc Connell, D., Cant, R. & Westbrook, M. (1999) Support network of mothers with intellectual disability: an exploratory study. *Journal of Intellectual Developmental Disability* 24, 7-26.

Llewellyn, G., Mc Connell, D. & Ferronato, L. (2003) Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse and Neglect*, 27, 235-251.

Masson ,J., Pearce, J. and Bader K. with Joyner. O , Marsden J and Westlake D (2008) Care Profiling Study London: Ministry of Justice Research Series 4/08.

Mayes, R., Llewellyn, G. & Mc Connell, D. (2006) Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of Disability Research* 8, 120-131.

McCarry, A., Kroese, B. and Cox, R. (undated). *Doula support for mothers with learning disabilities*. Personal communication.

McConnell, D. & Llewellyn, G. (2000) Disability and discrimination in statutory child protection proceedings, *Disability and Society*, 15 (6) 883-895.

McConnell, D. and Llewellyn, G. (2005) Social inequity, the deviant parent and child protection practice. *Australian Journal of Social Issues* 40, 553-556.

Mc Connell D, Llewellyn, G. & Ferronato, L (2006) Context contingent decision making in child protection practice. *International Journal of Social Welfare* 15, 230-239.

McConnell, D., Feldman M., Aunos, M & Prasada, N. (2011) Parental cognitive impairment and child maltreatment in Canada *Child Abuse & Neglect* 35 (621– 632).

McGaw, S. & Newman, T. (2005) What works for parents with learning disabilities? Ilford, Barnardos.

Munro, E. (2011) *The Munro review of child protection: final report: a child-centred system*. Norwich: The Stationery Office (TSO).

McGaw, S., Shaw, T. and Beckley, K. 2007) Prevalence of psychopathy across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 11-22.

Perkins, T. S., Holbourn, S, Deaux, K., Flory, M. J., and Vietze, P. (2002) Children of mothers with intellectual disability: Stigma, mother-child relationships and self-esteem. *Journal of Applied Research in Intellectual Disabilities*, 15, 297-313.

Pixa-Kettner U. (1998) Parents with intellectual disability in Germany: results of a nation-wide study. *Journal of*

*Applied Research in Intellectual Disabilities* 11, 355–64.

Pixar-Kettner U (2008) Parenting with intellectual disability in Germany: Results of a new nationwide study.  
| *Journal of Applied Research in Intellectual Disabilities* 21, 315-310.

- Ronai, C. R. (1997) On loving and hating my mentally retarded mother. *Mental Retardation* 35, 417-432
- SCIE (2005) *Helping parents with learning disabilities in their role as parents*.  
<http://www.scie.org.uk/publications/briefings/briefing14/index.asp>.
- SCLD (2009) *Scottish Good Practice Guidelines for Supporting Parents with Learning Disabilities*. Glasgow, SCLD
- Sigurjonsdottir, H. B. and Traustadottir, R. Parenting and Resistance: Strategies in Dealing with Services and Professionals. In *Parents with Intellectual Disabilities, Past, Present and Future* Eds G Llewellyn, Traustadottir R, McConnell C and Sigurjonsdottir H B (2010) Wiley Blackwell, West Sussex.
- Stevenson, O. (2007) *Neglected children and their families* (2nd edition). Blackwell, Oxford.
- Tarleton, B., Ward, L. & Howarth, J. (2006) *Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children*. London, Baring Foundation.
- Tarleton, B. (2006) *Providing the right support? Evaluating the work of the north east parents support project and the Walsall Parents advocacy services*. Internal report for Mencap. Bristol: Norah Fry Research Centre.
- Tarleton, B. (2008) Specialist Advocacy services parents with learning disabilities involved in child protection. *British Journal of Learning Difficulties*, 36, pages 134-139.
- Tarleton, B., Porter, S., Brown, L. & Davis, L. (2011) *Evaluation of the Valuing Parents Support Service*. Internal report for funder. Norah Fry Research Centre, Bristol.
- Tymchuck, A. J. (1992) Predicting adequacy of parenting by people with mental retardation, *Child Abuse and Neglect* 16 (2) 165-178.
- Ward L (2008) *Facts and figures about parents with learning disabilities in England*.  
<http://www.bristol.ac.uk/wtwpn/resources/facts-pwld.pdf>
- Weiber, J., Berglund, P., Tengland, A. & Eklund, M. (2011) Children born to women with intellectual disabilities 5-year incidence in a Swedish county *Journal of Intellectual Disability Research* 55 part 11 pp 1078–1085.
- Willems, D., De Vries, J. N., Isarin, J. & Reinders, J (2007) Parenting by persons with intellectual disability; An explorative study in the Netherlands. *Journal of Intellectual Disability Research* 51, 7, 537- 544.
- Working Together with Parent Network (2009) *Supporting parents with learning disabilities and difficulties – Stories of positive practice*. Bristol, Norah Fry Research Centre.