An introduction to parents with learning difficulties

The number of parents who are recognised as having difficulties with learning is growing (see the paper on facts and figures). A minority of these parents have a diagnosed learning disability as they have an IQ of less than 70. The English Good Practice Guidance on Working with Parents with a Learning Disability (DoH/DfES 2007) uses the definition of learning disability in the White Paper, Valuing People. It states that ‘learning disabilities includes the presence of:

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

However, many people who have a diagnosed learning disability prefer to use the term ‘learning difficulty’. They feel that the term ‘learning disability’ implies that they can not learn at all. The term ‘learning difficulty’ is preferred by the People First movement in the UK.

There is a far wider group of parents with learning difficulties, who do not have a diagnosis and would not generally fit the eligibility criteria for support services in their own right (Department of Education and Skills 2003). These parents often recognise that they need practical support and help to enable them to learn to be the best parents possible (Tarleton et al 2006). This group is described as the ‘hidden majority’ by Edgerton (2001). We do not know how many parents there are who may struggle with reading, writing, remembering, decision making etc. The most recent figures, from the first national survey of adults with learning disabilities in England found that one in 15 of the 2,898 adults interviewed had children (Emerson et al, 2005).

The literature suggests that there is no direct link between IQ and parenting ability above the IQ level of 60 (IASSID SIRG 2008). Parents with learning difficulties face a wide range of barriers to bringing up their children successfully.

Barriers to parenting

Parents with learning difficulties 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 are often seen as childlike and 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, Sigurjonsdottir and Traustadottir 2000, Mayes et al 2006).

Once involved in the parenting process, parents face:

- Negative expectations about their parenting ability. Their learning 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 (Cooke 2005, CHANGE 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)
- Use of IQ levels as a proxy for parenting ability without detailed assessment of their abilities and support needs
- Fixed ideas about what should happen to their children (Tarleton et al 2006)
- 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)
- 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,
- Mainstream services that are not equipped to work with parents with learning difficulties (Goodringe 2000, Tarleton et al 2006). This point is returned to in section on the practice reality

Parents are also:
- fearful of asking for help with their parenting. They 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 in the past
- facing a wide range of disadvantages including unemployment, poverty, poor housing in difficult neighbourhoods where parents report harassment and bullying. They are also likely to have difficulties such poor physical health, mental health support needs, substance abuse, domestic violence or had themselves grown up in care (SCIE 2005, Cleaver and Nicholson, 2005, Tarleton et al 2006).

Supporting successful parenting

There is no conclusive evidence why some adults with learning difficulties succeed in their role as a parent and others do not. However, factors reported consistently in the literature include:

- A positive informal support network
- Competence building support which helps parents to learn and achieve for themselves
- Parents are not overcoming personal traumas
The literature clearly points towards the importance of social support for parents with learning difficulties and 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 recent survey of adults with learning difficulties indicated that 9 out of 10 mothers who were living with relatives had their children with them in contrast to 4 out of ten mothers who lived in their own households (Emerson et al 2005).

Recent literature around parenting in general and supporting parents with learning difficulties more specifically indicates that better parenting can be supported in various ways. 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
- Interventions that build on parents’ strengths and promotes children’s resilience while modelling good practice. These interventions should be provided in the parent’s 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 which builds on parents’ existing skills and abilities, praises their successes and promotes their social integration
- 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)


The English Good Practice Guidance on Working with Parents with a Learning Disability (DoH/DfES 2007) and Scotland Guidelines for Supporting Parents with Learning Disabilities (SCLD 2009) state 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 Practice reality

Tarleton et al (2006) suggest that a number of services around the UK are endeavouring to provide appropriate support to adults with learning difficulties so that
they can parent to the best of their ability. A recent publication by the Working Together with Parent Network (2009) presents six ‘success stories’ which discuss positive practice in supporting parents with learning difficulties.

However, it appears that this positive practice is not consistent across the UK. Positive practice is developing where:

- local professionals have an interest in parents with learning difficulties,
- local professionals receipt of increasing numbers of referrals for support or
- there have been ‘contested cases’ where local professionals, generally from mainstream or adult services, believe that children have been removed from families unnecessarily and that the parents could have brought up their children themselves with appropriate support.

It has also been found that pro-active multi-agency support for parents is inhibited by lack of co-ordination between services and a lack of understanding of different teams’ roles and perspectives. In addition, parents do not meet eligibility criteria because their learning difficulties are ‘not severe enough’, which means they are unable to access support from adult learning disabilities teams (Department of Education and Skills 2003) even though the policy guidance relating to both children’s and adults services indicates that preventative support should be provided. Some adults’ services are also reported as being resistant to working with parents with learning difficulties, seeing them as the responsibility of children’s services or yet another client group that requires support, without additional funding, and as often involving court work for which adult social workers are not trained (Booth and Booth 2004, Tarleton et al 2006).

It is reported that children’s social workers currently have little experience of working with parents with learning difficulties and often hold stereotypical attitudes to their parenting ability. Cleaver and Nicholson (2005) also recognised that it is unrealistic to expect children and family social workers to have the expertise and specialist skills needed to work with parents with learning difficulties and that there was little evidence of these workers making use of the skills held by colleagues from a learning difficulties backgrounds or relevant resource or tool kits (such as the Parent Assessment Manual, McGaw et al, 1997).

The support available to parents often appears to be short term in response to a difficulty or crisis which has brought them into contact with children’s services rather than long-term and preventative as advocated by the English Guidance (2007) and Scottish Guidelines (2009). The provision of short term support is believed to result in a cyclical pattern of improved parenting when provided with support which leads to a reduction in concerns and the support provided. This reduction of support leads to a decrease in appropriate parenting and an increase in concerns. It is also believed that children’s social workers often do not have a concept of, or finance for, long term support and that professionals tend to be narrowly focused on ‘protecting the child’ and reducing risk to children through looking towards permanency with another family rather than compensatory support services for their natural family (Tarleton et al 2006).

Parents involvement with Children’s Social Care
It has been found that the concerns raised about the welfare of children of the parents with learning difficulties relate to inadequate childcare rather than abuse (Llewellyn et al 2003, Tymbchuck 1992) and children are placed on the child protection register in relation to concerns regarding:

‘neglect by omission [and] is a result of a lack of parental education combined with the unavailability of supportive service’ (Cleaver and Nicholson, 2005).

Estimates vary, but Emerson et al found that forty percent of parents were not living with their children. 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) however, found that in less than twenty percent of cases involving parents with learning difficulties, across 10 authorities, the children were permanently removed and that most were fostered rather than being adopted.

When children are removed from parents with learning difficulties, there are also other factors present such as mental health/physical health problems, substance abuse, isolation from friends, poverty, inadequate housing (Cleaver and Nicholson 2005). The children of parents with learning difficulties are known to have high levels of need but their parents are not receiving the type of support which will improve the outcomes for their children.

This lack of support is an infringement of children and parents’ human rights. A Life like Any Other (Joint Committee on Human Rights, 2008) recognised

“ that unless justified by a proportionate and necessary response to a risk to the child, …. compulsory removal of a child from the care of its parents poses a significant infringement on the rights of both the child and its parents, to respect for their family life” (page 59).

Parents views of the Child Protection/Legal System

Parents with learning difficulties report their fear of engaging with services concerned with the welfare of their children at a time when parents are expected to work in partnership with services. Parents feel that Children and Families services:

- Do not understand people with learning difficulties
- Do not listen to them
- Expect them to fail
- Do not give them clear messages about what is expected of them
- Treat them differently from other parents who need support
- Use their need for support, or any difficulties with their child, against them as evidence that they can not parent
- Use their previous history of having children removed, when they have not been provided with adequate support, against them
- Provide no support once their children have been taken from them (Tarleton et al 2006).

These ideas have been discussed in the literature as ‘system abuse’ and ‘institutional discrimination’ against parents with learning difficulties (Booth and Booth, 2004, Booth et al, 2005a and b, McConnell and Llewellyn, 2000).

Booth and Booth (2004) reported that parents found case conferences harrowing and lonely meetings where they often did not know what was happening or who the large numbers of professionals involved were. Parents felt they were not listened to and disempowered in the formal atmosphere of over-long child protection conferences where inaccurate statements were often made about their parenting and they were often unable to follow the discussion.

Parents also reported being scared about going to court where they did not understand and were not prepared for what was happening. They also reported feeling embarrassed and left out by the court system and humiliated by their interrogations in the witness box (Booth and Booth 2004). McConnell and Llewellyn (2000; 2005) also report that parents have difficulty in instructing a solicitor and are often not advised to seek legal advice by children’s services.

There is a clear call for parents to be supported by an advocate and research has clearly shown the benefit of an advocate ensuring parents understand and engage with the child protection and court processes (Mencap 2006). Booth and Booth (1998) recognise that advocates can prevent bad practice and competence inhibiting support making the parents’ situation worse but not change what happens to parents in the long term. However, the recent Mencap (2006) report highlighted the potential of a specialist advocate, who knew the parents well and understood parents' support needs as well as the child protection system, to enable parents to really engage with the process, understand and respond to the concerns regarding their parenting.

References


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